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## HOW AND BY WHOM ARE THE CURRENT AND ANTICIPATED FUTURE SUPPORT NEEDS OF ADULTS WITH AUTISM SPECTRUM DISORDER MET?

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**HOW AND BY WHOM ARE THE CURRENT AND  
ANTICIPATED FUTURE SUPPORT NEEDS OF ADULTS  
WITH AUTISM SPECTRUM DISORDER MET?**

**Valerie Anne D'Astous**

**Thesis submitted in fulfilment of the requirements for the  
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King's College London**

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This thesis is dedicated to my mother, Veronica Cowie, from whom I learned the value of perseverance and tenacity, patience and kindness.

## Abstract

This thesis explored current, and anticipated future health and social needs, and support provisions of adults with ASD, from their own and family members' perspectives. Using a cross-sectional mixed methods research design, 74 adults with ASD completed the Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID) and 49 family members participated in semi-structured, face-to-face individual interviews. Additionally, a comparative analysis of two age groups of adults with ASD (18-29 and 30+) was undertaken to investigate similarities and differences in reported need and support provision. Knowing what the health and social support needs of adults with ASD are is the first step in understanding how to best meet them.

Quantitative findings suggest there may be an association between age and the level of support needs among adults with ASD. Older adults aged (30+ years of age) had greater levels of support need, and unmet support in comparison with younger aged adults (18-29 years). Specifically, high unmet needs of comorbidities of mental illness were reportedly unaddressed in this sample. Qualitative findings provided depth, details and varied perspectives of the lived experiences and support needs of adults with ASD. Results highlight a void in supportive services for adults with ASD with family members attempting to fill the adults' support needs. The stability and continuity of family relationships and support for adults with ASD was emphasised but results suggested it may be diminished or absent in the future with greater need for formal support. Moreover limitations in communication, and skills of daily living placed adults with ASD at risk of harm and exploitation without adequate and effective support. Future support, wellbeing and safety of adults with ASD were primary family concerns but few had developed emergency or future support plans. These findings have relevance for service providers and public policy.

## Statement of contribution

This thesis is the result of my own independent work. However, significant contributions to the conception and design of the project, data collection and data from the NIHR funded project, *Crossing the divide: Effective Treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability*, warrant mention and explanation. The same design, measures and protocol for data collection used in this previous project were also employed in this study. Namely, the Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities (CANDID) (Xenitidis, 2003) and a modified version of the Client Service Receipt Inventory (CSRI) (Chisholm et al., 2000) questionnaires were used, as well as the same format, of face-to-face meetings with participants with the researcher reading the questions and recording the responses on a paper copy, was followed. Furthermore, data collected from 46 participants in the Crossing the divide project, who met inclusion criteria, were included in the quantitative stage of this study. As such, I personally only collected data from 8 younger adults with autism and 20 older group participants for the quantitative portion of this research.

In addition to building on quantitative aspects of the *Crossing the divide* project, this study distinctively included a qualitative research design to gain an understanding of the support needs and family future support plans for adults with autism from a holistic family perspective. I conducted 49 qualitative interviews with adults with autism, their parents, partners and siblings. Furthermore, acknowledgement must be given to Taggart and colleagues (2012) for allowing me to modify and use the interview topic guide they developed to explore family carers' future plans for an adult son or daughter with an intellectual disability.

This was a self-funded study with in-kind administrative support provided from research staff at the Institute of Psychiatry, King's College London who provided me with database patient information, for participant recruitment.

## Abbreviations

Abbreviations that are used in this thesis are listed below in alphabetical order.

ADI-R	Autism Diagnostic Interview-revised edition
ADOS	Autism Diagnostic Observation Schedule
ASD	Autism Spectrum Disorder
BAP	Broad Autism Phenotype
CANDID	Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities
CSRI	Client Service Receipt Inventory
DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Classification of Diseases
NAS	National Autistic Society
NHS	National Health Service [of the UK]
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics [of the UK]
SD	Standard Deviation
UK	United Kingdom

## Glossary

The thesis uses terminology as described below.

### Autism spectrum disorder (ASD)

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder with symptomology of social communication deficits and restricted, repetitive behaviours, interests, or activities. It is a lifelong disorder with symptoms evident in childhood. The effects and severity of symptoms are different for each person (American Psychiatric Association, 2013). Different groups and individuals also use autism spectrum conditions, autistic spectrum difference or neuro-diversity, and often autism is used as an umbrella (Department of Health, 2010). The thesis uses ASD for all individuals with an autism spectrum disorder, and uses the term autism when describing ASD historically in Chapter 2.

### Support

‘Support’ is the term used in this thesis to describe a wide range of help that an adult with ASD needs in order to live in the best way he or she can. It includes the help provided informally by family and friends and formally through health and social services.

### Services

The term ‘services’ in this thesis refers to formal support, provided by professionals or trained employees who are typically paid for their work. These services may be offered by government agencies, by commercial agencies, by not-for-profit agencies or even by informal support networks. Services can include assessment and diagnosis, community care, home-based services, accommodation and housing, employment, and finance benefits.

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## **Chapter 1: Introduction and background to the research**

This thesis concerns the support needs of adults with autism spectrum disorder (ASD). It explores the current and anticipated future support needs of adults with ASD from their perspective and that of their parents, partners and siblings. The study focuses on a wide range of social, physical and mental health needs and how support needs are, or are not, being met. The study is supported by the assessment and triangulation of cross-sectional data obtained from quantitative questionnaires and qualitative interviews with multiple family members. In this chapter the research aims are provided, autism and ageing with autism are described, the theoretical perspective used is identified and research gaps in this area are discussed. The chapter concludes with a description of the structure of the thesis.

### **Research aims and objectives**

The aim of this research is to explore the support needs, family roles and relationships and long term support planning in families with an adult with ASD from a holistic family perspective. The choice of topic reflects a growing concern about the continuity of support for individuals with ASD as they transition to adulthood and their needs go beyond the support that parents can provide. The life course perspective is applied to understand past experiences, the present situation and anticipated future support in families with an adult with ASD. In order to achieve the research aim a mixed methods design was used. The main objectives are:

1. To identify the current support needs and service use of adults with ASD.
2. To explore family relationships, role changes, concerns, preferences and future support expectations from the perspectives of adults with ASD, their parents, partners and siblings.

The first objective guides the analyses towards an understanding of the individual support needs of adults with ASD and how and by whom support needs are met; conceptualising both health and social factors as determinants of current support needs. In addition age group comparisons of support needs may situate the individual within the influences and

experiences of their early life social historical context. The second objective acts as a follow up to the first objective by embedding the support needs of adults with ASD within the wider context of family relationships, experiences, and perspectives. Furthermore, it serves to qualify and extend quantitative findings, investigating the continuity of support across the life course for adults with ASD through the future plans of families.

To achieve the aim and objectives of this research, data were collected from a sample of adults with ASD, their parents, partners and siblings using both quantitative and qualitative research methods. Validated, standardised questionnaires were used to explore the characteristics, support needs, and service use of adults with ASD. In addition, face to face interviews were conducted with multiple family members to explore family relationships, patterns of support and perspectives of future needs and support for adults with ASD. The study was designed to determine the extent to which the support needs of adults with ASD are recognised and met. It highlights age differences in support needs and provision of adults with ASD. In addition, it raises questions about how and what support needs are assessed and underscores areas of unmet support needs for adults with ASD. The findings of this research have implications for service providers, policy and practice.

## **Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability which produces a wide range of cognitive and neurologic impairments (Landrigan, 2010). It is one of the most common developmental disabilities, affecting individuals of all races, ethnic and socioeconomic backgrounds (Geschwind and Levitt, 2007). Autism has no single known cause. Many causes have been proposed and will be briefly outlined in the next chapter on the historical context of autism (Chapter 2). No biological “test” exists for ASD (Baird et al., 2003). It is defined by behavioural symptoms which present in varying degrees of severity across a range from mild to severe (CDC, 2016). Thus the terms autism spectrum disorders or conditions (ASD or ASC) are used. Two core symptoms categorise ASD: impairments in social communication (verbal and nonverbal) and restricted and/or repetitive behaviours (American Psychiatric Association, 2013). These symptoms must cause some degree of functional impairment (Hyman, 2013) and manifest before the age of 3 years (American Psychiatric Association, 2013). ASD is almost five times more common in boys than in girls

(CDC, 2016). It is a lifelong disorder that affects how the individual communicates with and relates to other people and the environment (Cederlund et al., 2008, Howlin et al., 2004). Many people with an autistic spectrum disorder also have a learning disability and usually need specialist care and education (Baird, 2003).

Although individuals with ASD share common 'symptomology', these symptoms may appear in a multitude of combinations and vary in intensity. Thus individuals diagnosed with ASD are a very heterogenic group with manifestation of the disorder varying from individual to individual. For some the symptoms may be mild, with minimal functional limitations, while for others the symptoms are so severe that they are functionally disabled. Thus some adults with ASD may be considered high functioning (but with idiosyncratic social skills and behaviours) while others may have less functional abilities, be nonverbal and asocial. Unusually repetitive ways of thinking and behaving are also seen in people with ASD. This can take such forms as becoming overly preoccupied with narrow interests such as collecting objects, or facts about a particular topic, or maintaining very rigid, obsessive routines (Matson et al., 2012). Some people with ASD may have repetitive movements such as flicking their fingers or flapping their hands.

The majority of people with ASD have sensory perceptual problems (Bogdashina, 2016; Gonthier et al., 2016). Sensory problems can impact behaviour, sleep, learning and socialisation. Sensitivities to light, sound, texture and touch may have a profound effect on an individual's social and environmental interactions. Additionally, auditory and visual processing abnormalities in a wide range from mild to severe and have been identified (Marco et al., 2011). Some research has reported diminishing sensory abnormalities with age (Kern et al., 2006), whereas others have described sensory impairments persisting across the lifespan (Crane et al., 2009). Sensory abnormalities may be highly disabling for adults with ASD influencing daily living skills (Liss et al., 2006), anxiety and depression (Pfeiffer et al., 2005) and behaviour disorders (Boyd et al., 2010). The impact of sensory perceptual problems for autistic people may require effective strategies and environmental adjustments to facilitate their optimal functioning and inclusion. Many children and adults with autism also have co-occurring health problems or comorbid conditions (Bauman 2010).

### **Comorbidities with ASD**

Comorbidity is the presence of one or more medical or psychiatric conditions, in addition to a primary disorder (Matson and Nebel-Schwalm, 2007). ASD tends to be highly comorbid with other medical (Bauman, 2010) and psychological conditions (Hofvander et al., 2009). Mannion (2013) reported a prevalence rate of 46 percent for a comorbid condition among children and adolescents with ASD including: epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), gastrointestinal symptoms and sleep problems. The prevalence rate increased to more than 78 percent when intellectual disability was included as a comorbid disorder (Mannion et al., 2013).

Intellectual disabilities frequently co-occur with ASD, with prevalence rates reported between 50-75 percent (Matson and Shoemaker, 2009, Volkmar et al., 2004). Intellectual disabilities is a broad term encompassing impairments in cognitive processing (Schalock et al. 2010). There are varying degrees of intellectual disabilities from mild to profound. Individuals with intellectual disabilities have functional impairments and limitations in the ability to learn, reason and make decisions (Matson et al., 2009).

Psychiatric comorbidities in individuals with ASD are high (Fombonne, 2012). In a study of comorbidities in adolescents with ASD, Simonoff and colleagues (2008) found that 70 percent had at least one psychiatric comorbid disorder and 41 percent had two or more. The most common psychiatric comorbidities were social anxiety, ADHD, and oppositional defiant disorders (Simonoff et al. 2008). A study examining psychopathology in a clinical sample of adults with ASD found a rate of 80 percent, with depression and anxiety disorder being the most prevalent (Ghaziuddin and Zafar, 2008). Other research has added a high rate of attention deficit hyperactivity disorder (ADHD) to the list (Joshi et al., 2012).

The association of epilepsy and ASD was recognised by Rutter in 1970 (Rutter, 1970). The prevalence rate of epilepsy in people with ASD ranges from 4-42 percent (Giovanardi Rossi et al., 2000). Epilepsy treatment requires medication and medical monitoring across the lifespan and it can have profound social, physical and psychological consequences. Researchers have found a comorbidity of epilepsy with ASD is associated with an increased rate of early death (Gillberg et al., 2010).

Having a comorbidity can profoundly affect an individual's physical and social abilities with detrimental effects on quality of life, morbidity and mortality (Boyd et al., 2008, Fillenbaum et al., 2000). The specific manifestation of ASD characteristics may change as children grow older, but the deficits continue into and through adult life with a broadly similar set of problems in socialisation, communication, and interest patterns (Seltzer et al., 2003). As such, the amount of support and the range of provisions needed for individuals with ASD exist on a continuum depending on their individual limitations and strengths. While some can live independently, most require a certain degree of support with the most severely affected requiring lifelong intensive support and services. ASD has lifetime consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life for the individuals themselves, and their families (Buescher et al., 2014, Lounds et al., 2007).

### **Ageing with ASD**

Historically, many people with lifelong disabilities did not reach old age. Medical and social advancements within the last 70 years have greatly altered life expectancy (Emerson and Baines, 2010). Older adults with ASD are a newly identified ageing population, yet, little is known about their profile as they age (Mukaetova-Ladinska et al., 2012). To date little research has been conducted to explain and describe the life course of ASD in older age (Bruder et al., 2012, Mukaetova-Ladinska et al., 2012). In all probability, it may be equally as heterogeneous as the condition of ASD, distinct to each person on the spectrum. Moreover, with institutional and policy changes the linked lives of parents and their children with ASD may be pronounced through continued practical and emotional support into adulthood and across their life course.

As people with ASD age, they face the same physical and mental difficulties common to all people who are ageing (Mukaetova-Ladinska et al., 2012). Yet, they also continue to have other conditions associated with ASD. Persistent medical conditions such as epilepsy, psychological conditions like anxiety or depression, outstanding levels of social and physical disability, and lasting behavioural challenges may all be additive to the normal ageing process for adults with ASD (Kohane et al., 2012). They may also need additional support to ensure they grow old in safety and with dignity (Renty and Roeyers, 2006). This section describes

current knowledge, considers expectant outcomes, and explains the difficulties in assessing, diagnosing and treating the medical, psychological and social aspects of ageing with ASD.

#### **Normative age-related changes and adults with ASD**

Health-related changes that occur with ageing fall into three categories: physical, psychological, and social (Peel et al., 2004). As changes begin to happen in one area of a person's life, most likely the other two will be affected as well (Hofer and Sliwinski, 2001). There is a wide variation among individuals in the rate of ageing and medical science does not yet know how the ageing process will present in adults with ASD. Ageing is a developmental process with gradual loss of or deterioration in all body systems (Rowe and Kahn, 1987). As adults with ASD age, they too will experience these age-related changes.

Sensory changes are part of ageing and can affect a person's lifestyle (Valentijn et al., 2005). All senses can be affected by ageing, but hearing and vision are most affected. Visual and hearing impairment can have negative consequences on socialisation and may contribute to social isolation in older people (Crews and Campbell, 2004). For an adult with ASD with limited social and communication skills, visual and hearing changes may not be verbally expressed. Nevertheless, the effects and frustrations may be experienced and displayed in behavioural change over time. Because atypical sensory based features are predominant in individuals with ASD monitoring changes across the life course is needed (Ben-Sasson et al., 2009, Gonthier et al., 2016). Like adults with Down syndrome, age-related visual and hearing loss may begin earlier in adults with ASD (Evenhuis and Natzgam, 1998). Timely detection and treatment to compensate for these changes is essential.

Age-related changes in bones and joints include osteoporosis and arthritis (Dequeker and Geusens, 1990, Loeser, 2010). Arthritis and bone deterioration are common problems linked to ageing and can have major effects on a person's quality of life, ability to work, and basic activities of daily living (Loeser, 2010). Adults with developmental disabilities have a high risk of osteoporosis and show severe degrees of bone demineralisation (Jaffe et al., 2001, Jaffe and Timell, 2003). Many people with ASD have very narrow or restricted dietary consumption, and limited participation in exercise which may increase their predisposition to osteoporosis as they age (Graf-Myles et al., 2013). Osteoporosis has no observable symptoms,

so screening for early detection in adults with ASD to avoid chronic disability is important (Kanis et al., 2002). Arthritis is another common disorder in advanced age, resulting in joint pain that can cause functional limitations and decrease an individual's quality of life (Reginster, 2002). Treatment aimed to maintain mobility, ease aches and pains associated with arthritis can be implemented for adults with ASD.

The cardiovascular and respiratory systems undergo changes with age. With age the elasticity of blood vessels and lung tissue is diminished, yet without pathological changes healthy functioning can be maintained (Sherratt, 2009). A study that looked at the general health of young adults with ASD found that without intervention, they appear to be at significant risk for developing diabetes, coronary heart disease, and cancer (Tyler et al., 2011). Mortality is increased in autism, with death rates being three to ten times higher than the general population (Bilder et al., 2013, Woolfenden et al., 2012). These deaths tend to be the result of medical comorbidities, such as epilepsy, gastrointestinal conditions and respiratory disorders (Bilder et al., 2013, Gillberg et al., 2010, Shavelle et al., 2001, Woolfenden et al., 2012). One study found that deaths from gastrointestinal and respiratory disorders were 40.8 and 24.5 times higher, respectively, in moderately to severely affected individuals versus typical peers (Shavelle et al., 2001).

Similarly, the normal human ageing process includes structural and functional brain changes. The basic cognitive functions most affected by age are attention and memory (Glisky, 2007). Although much research has focused on the neuroanatomical and neurophysiological changes in the brain in autism, how brain changes are manifest in ageing adults with ASD remains unclear (Mukaetova-Ladinska et al., 2012). To date, there are no longitudinal studies examining the trajectory of neurocognitive markers of ASD in older adulthood. A recent study suggested adults with ASD may experience less age-related decrease in cognitive functioning in comparison with their neuro-typical peers (Lever and Geurts, 2015). It has been suggested that adults with ASD may have a protective cognitive reserve against the damaging brain changes associated with ageing (Happé and Charlton, 2012). However, other studies suggest that cognitive decline with age among older adults with ASD is similar to typical ageing patterns among the general population (Geurts and Vissers, 2012) There is a

need for greater understanding of, and cognitive assessment tools to evaluate, the functional brain changes with advancing age of people with ASD.

The social aspects of ageing include maintaining independence, social activities and relationships often in a familiar community environment (Mukaetova-Ladinska et al., 2012). For adults with ASD autonomy, social and leisure activities and the familiarity of the home environment are no less important. Yet, for many adults with this disorder social opportunities and the ability to manage their own lives and to adapt to changes may be severely limited. A holistic picture of the ageing process in adults with ASD has yet to be described. However, common ageing features need to be perceptively monitored and attended to in adults with ASD to maintain their health and wellbeing. Undetected health and age related changes could have detrimental repercussions for an adult with ASD's physical, psychological and social welfare. Furthermore, the significant prevalence rates of medical and mental illness that co-occurs with autism may compound the ageing process.

#### **Chronic disease and adults with ASD**

Normal age-related changes often are exacerbated by the presence of chronic disease (Hopman et al., 2009). Chronic diseases are incurable diseases of long duration and generally slow progression, such as heart disease, stroke, cancer, chronic respiratory diseases, Alzheimer's disease and diabetes. Chronic diseases constitute a major cause of mortality. No autism specific findings for chronic disease exist in the current population of older adults with ASD. However, in a forward looking research study examining risks for chronic disease in adulthood for individuals with ASD, Tyler and colleagues (2011) emphasised the need for interventions and health care management to prevent future chronic disease in this population. The significantly high rates of obesity, high blood pressure and high cholesterol levels among their sample of young adults with ASD are all risk factors for the development of chronic diseases. Lifestyle risk factors may explain in part these heightened risk factors. Promoting healthy eating patterns, increased physical activity, and weight management in childhood and adolescence may decrease the risk factors of chronic disease (Darnton-Hill et al., 2004, Happé and Charlton, 2012).



Difficulties assessing, diagnosing and treating medical, psychological and social aspects of ageing with ASD.

Much more research needs to be conducted with the ageing population of adults with ASD to facilitate our understanding of specific age related differences, and to highlight areas for intervention to best support the health and wellbeing of adults with ASD into old age. As discussed, adults with ASD may have complex medical, psychological and social conditions (Happé and Charlton, 2012). However, medical and mental health disorders may go undetected and untreated (Wick and Zanni, 2009). Promoting health, effective management and decreasing chronic disease risk factors are essential to successful ageing for individuals with autism (Bruder et al., 2012). Routine health related screening for adults with ASD need to be carried out, including breast, cholesterol, colorectal cancer, diabetes, hypertension, prostate cancer and osteoporosis screening. Communication difficulties and sensory impairments may deter their ability to express any personal physical changes or pain and create barriers to medical care access (Kern et al., 2006).

Advocacy may be needed so that access issues (transportation, environmental modification, special equipment) are addressed to enable the provisions of primary health care are obtainable for adults with ASD. Adults with ASD may have difficulty cooperating during diagnostic, screening or treatment procedures. For example, sensitivities and behavioural distress may complicate the examination and cooperation with procedures essential to diagnosis and treatment. Family member's views and understanding of the medical circumstance should be acknowledged and assessed when available (Happé and Charlton, 2012). Health care providers (including physicians, nurses, and dentists) need training to deliver high quality health care to adults with ASD (Mukaetova-Ladinska et al., 2012). Limited educational knowledge and expertise with ASD among general practitioners may further decrease the recognition and management of comorbid conditions in adults with ASD (ibid). Careful observations, routine diagnostic screening, monitoring and appropriate interventions will enable adults with ASD to experience healthy quality of life into advanced ages.

Increased social opportunities and support across the lifespan are also crucial (Renty and Roeyers, 2006). Engaging adults with ASD as active participants in their wellbeing including enquiring and sharing their perspectives, needs and desires is essential. Their voice is largely

absent in research. Likewise the needs and support for family members devoted to supporting them must be recognised and addressed (Hare et al., 2004). Effectual communication and partnership between medical and social services, and adults with ASD and their family members is necessary to ensure healthy ageing with ASD.

An increasing number of studies are exploring ageing and ASD (Happé and Charlton, 2012, Perkins and Berkman, 2012), but few report the personal experiences and subjective support needs of adults with ASD (Damiano et al., 2014, DePape and Lindsay, 2015, Punshon et al., 2009). The core defining characteristics and associated complex multi-morbidities of ASD persist across the life course (Hare et al., 2004), commonly necessitating various individual support needs (van Heijst and Geurts, 2015). Adults with ASD are likely to need support across a range of areas including social, vocational, residential and health (D'Astous et al., 2016, Povey et al., 2011, Turcotte et al., 2016). Multifaceted combinations of individual medical, social and personal circumstances give rise to individualised needs. Yet, support needs may fluctuate and change across the life course, and vary within circumstances, environments and by age. Moreover, needs may be met in different ways at different stages of life. Formal and informal support to meet individual needs may include prevention, health promotion and intervention. Understanding support needs is important as research has suggested that the timing and effectiveness of support may impact the quality of life for adults with ASD (Renty and Roeyers, 2006). Knowing what the health and social support needs are for adults with ASD is the first step in understanding how to best meet them.

## **Research plan**

This study used a cross-sectional, sequential mixed research methods design with qualitative interviews following quantitative questionnaires. The quantitative aspect of this research built upon the findings of the NIHR funded study, *Crossing the Divide* which explored the 'service and support transition' to adulthood for individuals with ASD. It used the same quantitative instruments, protocol and some participant data. However, the new research design to extend the age range of adults with autism and to include family member participation in qualitative interviews required a substantial amendment to the ethical approval. The research proposal identified that a sample of up to 50 adults with autism in each of two age groups (18-34 and 35 and older) would be recruited for Stage One, the quantitative segment, with a subsample

of 10-15 families to be selected for participation in Stage Two, qualitative face-to-face, semi-structured interviews. It was anticipated that a large portion of the quantitative data for the younger age group of adults with ASD would be taken directly from the NIHR study. Recruitment for the older age group of adults with ASD was sought from the Behavioural Genetics Clinic (BGC) research database held at the Institute of Psychiatry, King's College London. A critical sampling issue was recognised early in the planning of this study in reference to age group assignment. The limited number of available older aged adults with ASD for recruitment from the selected sources resulted in the demarcation age between group assignments being decreased by 5 years to 30 years of age instead of 35. This age separation between a younger and older age group of adults with ASD was still believed to an operative division in reference to socio-historical changes in the context of autism and normative developmental achievements at this age. This is discussed further in the Methods, Chapter 5.

### **Theoretical framework: understanding adults with ASD through the lens of the life course perspective**

The conceptual framework which has informed and driven this research is based primarily on two key concepts from the life course perspective (Bengtson et al., 2012). Although not dismissing other key aspects of the life course perspective, this research pays particular attention to the critical part played by the socio-structural influences and interpersonal relationships that shape the life course. Most importantly, it is the interactions between the two which are essential to understanding the whole. As such this research has focused on the interplay between human lives and historical time, and linked or interdependent lives across the life course for adults with ASD and their families.

The life course theory has influenced the way in which this study was approached. The two key principles of the life course perspective used in this study directed the literature review, guided the methodological design and analyses. First, these principles are described and discussed and subsequently explained is how time and place, and linked lives informed this research. This study used current and retrospective data to explore different phases of the life course of adults with ASD. Using the life course perspective it endeavoured to understand their support need trajectories in relation to their social and historical environment.

## **Life course perspective**

The life course perspective considers how people's lives are formed and changed from birth to death based on interdependent relationships both within the family and within the context of society (Scott et al., 2004). The life course perspective posits that there is a complex interrelationship between an individual and the family, as well as with the social and historical context in which they live (Elder Jr, 1994). The social and historical environment in which an individual lives influences the experiences and choices available to them (Bengtson, 2009). The life course perspective presents a holistic framework to study interactions between individual lives and social and historical change over time. It facilitates the understanding and conceptualising of lives within the contexts of families, society and historical time (Kok, 2007). Moreover, the life course perspective emphasises that earlier life experiences shape an individual's choices and decisions, and influence later life situations and selections (Scott et al., 2004). Thus, the life course is viewed as a cumulative process in which interactions, experiences, choices, and behaviours at an earlier stage of life, made within the confines of the social and historical environment, may impact later life stages.

Elder's (1974) seminal study of the consequences of economic and social changes on children and families in the Great Depression was a driving force behind the development of life course perspective. It revealed adaptation processes and life patterns in the individuals who shared this experience. The longitudinal, life course strategy study followed 167 individuals born in 1920-1921 from elementary school age through to the 1960's to assess the physiological and psychological effects of the economic crisis of the Great Depression on their life course. The dramatic events of the Great Depression shaped the biographies of the entire generation not only in their formative years but throughout the life course (Elder, 1999). Elder's research suggested the major historical events and forces of society these individuals experienced impacted their lives into adulthood and also extended into subsequent generations.

Therefore to understand an older person's present situation and decisions for the future, it is necessary to consider the life course experiences that helped shape them. The historical and social environment in which a child with ASD is born and raised has an effect on them and their family and in turn may produce diverse support needs in adulthood. Appreciating the present individual and family situation as an accumulation of past experiences and decisions

may help explain the current support needs of adults with ASD and future anticipations and expectations for their support.

The life course perspective is predicated on the view that various factors, including development, relationships and resources can impact life outcomes (Seltzer et al., 2004). A life course research perspective has been used to study outcomes and symptom changes in individuals with autism over time. Since Kanner's follow up study of the first diagnosed eleven autistic children reported in 1943 a growing body of research has explored outcomes in autism across the life course (Barnhill, 2007, Eaves and Ho, 2008, Henninger and Taylor, 2013, Howlin et al., 2014, Howlin et al., 2000, Levy and Perry, 2011, Magiati et al., 2014, Renty and Roeyers, 2006, Rumsey et al., 1985, Seltzer et al., 2004) While early outcome studies used vague outcome criteria, more recently standardised measures of adult outcomes including social, vocational, and residential and quality of life aspects have been employed. Additionally widely varying sample sizes and follow-up time frames have been used. However, nearly all studies have agreed that commonly the outcome for most adults with ASD is poor, although how poor is defined and qualified differed across studies.

More specific than overall outcomes, research has explored developmental trajectories for individuals with ASD (Seltzer et al. 2004); family coping (Gray, 2006) and sibling relationships (Orsmond and Seltzer, 2007a, Orsmond et al., 2009, Orsmond and Seltzer, 2007b) over time. A number of research studies from the US, UK and Japan have compared core diagnostic symptoms at different life stages (Boelte and Poustka, 2000, Gilchrist et al., 2001, Piven et al., 1996) and explored symptom changes over time (Beadle-Brown et al., 2006, Gillberg and Steffenburg, 1987, Kobayashi and Murata, 1998); with an overall suggestion that the severity of symptoms improve over the life course although persistent impairments in multiple areas remain. More recently, Seltzer et al. (2003) assessed the stability and change in the pattern of autism symptoms in adolescence and adulthood with a sample of 405 individuals with ASD divided into two age cohorts (10-21 years; and 22 years and older). The majority of the sample continued to manifest symptoms of autism that met the diagnostic threshold, although improvements in the severity of symptoms were found among adolescents and adults who as children had received an ASD diagnosis. Age cohort differences were noted with adolescents showing less impairment in the domain of reciprocal

social interactions and more impairment in the restricted, repetitive behaviours and interests domain than adults. No differences were identified in severity of symptoms between cohorts in the communication domain. The authors proposed historical time differences in diagnostic practice, differential treatments and social support services, as well as individual developmental changes over time may explain these differences. In contrast, Fein and colleagues (2013) have reported optimal outcomes in a minority of individuals with ASD who no longer meet criteria for a diagnosis and have communication and social skills equivalent to typically developing individuals. However, symptom changes over time do not necessarily reflect support needs across the life course. There exists limited research from a life course perspective on support needs of adults with ASD over time. The key life course principles used in this research are subsequently described.

## **Key principles**

### *Interplay between lives and historical time and adults with ASD*

The interplay between human lives and historical time takes into account the direct and indirect influences of historic, demographic and social changes on individuals and their relationships over time (Hareven, 1977). Environmental context and social structure alter across the life course and influence individual, family and group developmental and social trajectories and outcomes. Changing opportunities and limitations create different socio-historical environments to which individuals are exposed (Elder, 1994). In an abbreviated historical timeframe, exponential scientific and sociological changes have occurred within the context of autism. Over the last 70 years or so, events and conditions for individuals with ASD and their families have created constraints and opportunities that have affected their choices and behaviours (see Chapter 2). These sources of change have directly and indirectly influenced both individuals with ASD and their families. Time and place and individual characteristics can influence whether or when a child with autism receives a diagnosis, as well as the availability of support services, and can influence individual and family experiences and outcomes over the life course.

People of different ages have lived through different historical eras and have had different life experiences. An age cohort is a group of people born around the same time (historically) and

in the same place (socially) (Hutchison, 2008). Substantive changes can have a cohort effect that differentiates the cohort's life patterns (Elder, 1998). For example, changes in technology and the technical potential of the internet has transformed interactions, communications and access to information which has altered the life patterns of the cohort of young adults today. With wide societal changes in autism understanding, awareness and interventions, over the last 70 years, each decade children with ASD have been exposed to different environments, resources, options, and restrictions. The influences of these differences may be reflected in the individual life courses. However, individuals are not only embedded within the societal environment, they are also situated in relationships across the life course. The life course principle of linked lives is discussed next.

#### *Linked or interdependent lives and adults with ASD*

This principle in the life course perspective considers the intricate interrelationship of individual and collective linked lives within families and social structures over the life course (Hareven, 1977). The intersections of linked lives occur within the family and extends beyond to include friends, teachers and community encounters (Seltzer et al., 2005). Lives are linked over time, and within changing historical and social institutions (Bengtson et al., 2012).

The family is the primary environment in which a child is socialised and nurtured with long lasting influences (Harm, 2000). Children's early relationships and experiences contribute significantly to their physical and emotional development, and may either impede or positively impact their growth and behaviour (Shonkoff et al., 2004). During childhood enduring social skills, personality attributes, and social orientations and values are established (Maccoby, 1992). The life course perspective principle of linked lives maintains that significant relationships such as a parent and child share mutually influential, interconnected developmental trajectories throughout their lives. Relationships are bidirectional and reciprocal (Morgan, 1988, Hutchison, 2008). An autistic child not only has an effect on the family, but the family has effects on the behaviour and adjustment of the child (Karst and van Hecke, 2012, Kelly et al., 2008, Morgan, 1988).

The family defines the explicit and implicit roles, rules, responsibilities and boundaries maintained within it (Maccoby and Martin, 1983). However, roles, rules and responsibilities

within a family may be influenced by individual personal needs and through the social environment in which they live (Bott and Spillius, 2014). For example, the needs of a child with ASD and the availability of services can affect the patterns of relating and interacting between family members. Over the life course individuals and families undergo a variety of transitions and trajectories in development, education, work, and roles. Earlier transitions exert enduring influences on later life patterns (Hareven and Masaoka, 1988). Some people with autism experience age-related transitions late or not at all. For example, they may leave home at an older age, may not marry, become parents or find employment. Many adults with ASD remain highly dependent on their family, with approximately 50-60% still living with their parents (Levy and Perry, 2011). This elongated pattern of residency may serve to enhance mutually interdependent relations and alter family roles and responsibilities.

Furthermore, family obligations and responsibilities are negotiated throughout the life course (Atkin and Tozer, 2013). Sibling relationships with a brother or sister with ASD across the life course may be at a heightened risk for negative well-being outcomes and poorer relationships (Orsmond et al., 2009). Family expectations of behaviours and responsibilities for siblings of an adult brother or sister with ASD may be openly expressed or covertly assumed (Burke et al., 2012). Additionally, over time changes in the family influence the relationship between the family, and social institutions, and public policy. For example, when a parent dies, a sibling may not be able or willing to assume responsibilities of support for a brother or sister with ASD or need additional carer support and formal services.

Relationships within the wider environment of peers, school and employment also have significant influences. Research on the life course development of individuals with mild intellectual deficits has emphasised that the social support received from multiple contexts, such as school and community has independent and additive influences on individual school performance, social behaviours and mental health indicators (Seltzer et al., 2005). However, the behavioural challenges and social limitations of ASD may make it difficult for individuals to establish and maintain supportive peer relationships (Kelly et al., 2008). A follow-up study of adults with ASD (aged 22-47 years) found that almost half (47%) self-reported to have no peer relationships (Orsmond et al., 2004).



Relationships may be continuous across the life course or be disrupted and discontinuous (Giele and Elder, 1998). Moreover, all relationships are influenced by the cultural, institutional, social, and psychological environment in which they take place (ibid). The following section describes the rationale for using the life course perspective in this study.

### **Rationale for using the life course perspective**

It is within the context of historical changes in autism and the retrospective, current and prospective linked lives of families that this research explores the support needs of adults with ASD. Using the life course perspective it is hypothesised that significant historical and social changes in the context of autism have affected the current support needs of adults with ASD and may influence future expectations and decisions to meet their support needs. This research considered two age groups of adults with ASD to identify any possible cohort effects from significant historical and social changes they experienced. An older cohort of adults with ASD and their parents may have experienced limited social support and resources in an environment with a narrow awareness of autism. Older adults with autism may have encountered restrictions in educational opportunities and/or outmoded therapeutic interventions during their formative years. A younger cohort of adults with ASD may have received early interventions and inclusive education with their parents having wider access to information and social supports. The life course perspective posits that differences in early life experiences have a bearing on subsequent options and choices. These early experiential differences and personal decisions may be evident in the current circumstances of adults with ASD and future plans, aspirations and expectations to meet their support needs.

The principle of ‘linked lives’ and the importance of interactions in families of an adult with ASD is central to understanding how support needs are met across the life course. The values, preferences, interests, skills, and expectations of adults with ASD and their siblings have been primarily learned in the process of nurturing and socialisation in the family and secondarily through the economic and historical environment in which they were raised. Family is important in later life as during childhood. Yet, family relationships of adults with ASD remain largely unexplored (Dillenburger and McKerr, 2014). Across the life course many parents continue to provide support and resources for their adult children with ASD. However, in all likelihood they will outlive their parents and may require continued support

to maintain their wellbeing. Linked lives and experiences across the life course within families may influence how prepared families with an adult with ASD are to meet their future support needs. Moreover family expectations and sibling relationships may affect how future responsibilities for support of an adult brother or sister with ASD are anticipated to be met. In addition, changes in family demographics over time may result in a host of different family dynamics for an adult with ASD including no siblings, half-siblings or step-siblings, with different future support expectations post parental care.

However, the life course perspective is not without critique and a number of weaknesses or limitations have been identified. The rationale of being able to predict later life outcomes based on an earlier social-historical timeframe in the individual's life has been criticised. Some scholars have suggested that applying context as something carried forward disregards the possible effects of subsequent and/or current influences and experiences on the individual's life (Dannefer and Michalowski, 2006). Researchers have expressed that the life course perspective does not consider the diversity of experiences on a global level, with assertions that it only applies to affluent, late industrial societies (Dannefer and Michalowski, 2006, Fry, 2003). Others have posited that the life course perspective fails to adequately link the micro world of individual and family lives to the macro world of social institutions and formal organizations (Hutchison, 2010). As the life course perspective has continued to evolve, it has more clearly emphasised the links between life events and transitions of childhood, adolescence, and adulthood on an age-graded criterion (Shanahan, 2000). The life course perspective primarily embeds individual lives into social structures largely through their engagement in social positions and roles at the level of social interactions and organisations and the outcomes of these participation patterns. As such it may fail to fully incorporate the experiences of adults with ASD who do not neatly fit within these age-graded patterns.

## **Thesis structure**

This section provides a brief description of the ten chapters that comprise this thesis. An introduction to the study is presented in Chapter 1. The introductory chapter has two objectives: to provide the context of the study and to set out the conceptual framework. In the first part, the research aims and objectives, and the background and significance of the topic are identified. The second part of the chapter sets out the conceptual framework,

describing in particular the two key principles of the life course perspective: the interplay between lives and historical time; and linked or interdependent lives, which provide the lens through which the support needs of adults with ASD are explored and interpreted. The life course perspective then guides the thematic review of relevant literature (Chapters 2 through 4).

Chapter 2 traces the historical context of autism to help situate current understanding and to describe the different medical and social environments adults with ASD of different ages and their family members may have experienced. The life course perspective of the interplay between human lives and historical time infers the past experiences may influence the current situation for adults with ASD and their family. Thus a consideration of the historical setting of autism may be germane to appreciating the current and future support needs of adults with ASD.

Chapter 3 outlines the current context of community care and support services for adults with ASD in the UK describing existing social policies relevant to adults with ASD. It begins with a discussion of the medical and social models of disability to underscore the present socio-political perspective of disability and how ASD may be considered within these paradigms. Neurodiversity and the neurodiversity movement are described and discussed. It concludes with a brief description of the service provision and eligibility for adults with ASD. Chapter 4, the last literature review chapter, situates adults with ASD within the family. It discusses family relationships and support roles overtime when a child, sibling or partner has ASD. Gaps in the knowledge of the support needs, family relationships and future support planning for adults with ASD were identified throughout the literature review chapters and informed the research questions of this study.

Chapter 5 describes the research process and methodology, indicating ontological and epistemological positions. This is a mixed method study which takes a life course perspective. The chapter begins by explaining the rationale and choice of the research design. It details the quantitative and qualitative stages of the study identifying the sample, recruitment process, and research instruments for each stage. An explanation of ethical considerations and data analyses conclude the chapter.

The next four chapters (Chapters 6 through 9) report on the analysis. Chapter 6 describes the findings of the quantitative analysis of the CANDID and CSRI questionnaires completed by 74 adults with ASD. The analysis showed differences in the amount and areas of support need, unmet needs and service use between the two age groups of adults with ASD. Adults 30 years of age and older reported more areas of need, greater informal support provision and service use than adults 18-29 years of age. The CANDID domains were grouped into three broad categories for ease of reporting and to provide clarity of the findings. They include: general health, social relationships and general welfare. The next three qualitative analyses chapters describe findings from the semi-structured interviews with 49 family members. They are broadly structured into the three categories created in Chapter 6 and findings are discussed relative to the two principles of the life course perspective. Under the heading of general health, Chapter 7 details two key themes that were identified through analysis: a diagnosis of autism and the persistence and impact of mental illness. The process of receiving a diagnosis of ASD differed between the two age groups of adults with ASD and influenced their experiences and support provision in childhood. Most older adults with ASD did not receive a diagnosis until adulthood and did not experience any formal social support as children. Most younger aged adults were diagnosed with ASD in childhood and they experienced educational support, more information and professional interventions. However, the findings underscored the limited support available for individuals with ASD in adulthood. Chapter 8 describes the social networks of bonding, bridging and linking of adults with ASD under the broad category of social relationships. It identifies that most adults with ASD have limited social networks, restricted to primarily bonding networks with family members. However, analysis suggested that close family bonding networks of many adults with ASD may diminish or be absent in the future with a greater need for formal support. Chapter 9 explores the general welfare needs of adults with ASD and how family are prepared to meet their future support needs post-parental support. Key findings highlight welfare support needs for adults with ASD in the areas of money management, exploitation risks and independent living. Contested family perspectives of the abilities and support needs for adults with ASD were identified through text analysis. Few families had concrete plans or preparations to meet the future support needs of an adult family member with ASD.

Chapter 10, the concluding chapter, provides an overall discussion of the findings and situates them within previous research. This chapter also revisits the aims and objectives of the study, and summarises the key messages. The strengths and limitations of the study are outlined, areas for further study are identified and the life course perspective is critiqued. To end the chapter and the thesis I return to the beginning and reflect on the people who inspired me and contributed to the outcome of this study and draw some conclusions.

## **Chapter 2: Acknowledging the past to understand the present: a brief history of autism**

This chapter presents a timeline of the historical context in the recognition and definition of autism, briefly tracing the changing etiological theories and modifications in diagnostic criteria. The medical history of autism may be brief in time but it has lasting implications for the individuals and family members who have experienced its convoluted course. Likewise the social milieu, initially one of a blameful, stigmatising nature through to the mobilisation of awareness and advocacy, has altered the services, policies and resources for individuals with autism and their families.

Changes in the knowledge, diagnosis and interventions for autism have been consequential in shaping the life course experience of adults with autism. Likewise these transformations have influenced family relationships and roles over time. In order to grasp an appreciation of the contemporary context of ASD and adults living with ASD today, this chapter provides a brief overview of the historical medical and social changes that have transpired over time. Where once institutionalisation was considered the preeminent action of choice for this incurable disorder, early intervention and community integration for optimal outcomes is the current approach. From parental passive acceptance of incapacity to effective challenging of authority, to self-advocacy by individuals on the autism spectrum the bar of understanding and recognition of ASD continues to be raised.

The first generation of children diagnosed with autism is now entering old age and yet they remain poorly understood, under-recognised and under-researched. How they will age with ASD and the supports they need are as much a mystery as was treating them as children 60 years ago. The limited services and resources available to them as children seem to be perpetuated in their adulthood. Capturing their experiences and perspectives of their past, the present and anticipated future support needs will help inform what services are needed and help create a foundation for the generations that follow.

## Aetiology

### Autism as a psychiatric disorder

American psychiatrist Leo Kanner was the first clinician to delineate the specific symptoms of autism as a distinct childhood psychological condition (Kanner, 1943). Kanner labelled these children as having 'infantile autism'. The term autism had previously been used by Eugen Bleuler (1911) referring to schizophrenic individuals' withdrawal from the external world (Hollin, 2016, Kanner, 1965, McNally, 2009). Autism was derived from the Greek word "auto" meaning self. Kanner qualified that the children described in his case studies had not withdrawn from participation, rather they had never participated. His key diagnostic criterion was the child's lack of social interactions, notable since birth. He described their intense and narrow focus on moving or spinning objects and their penchant for consistency and sameness. Kanner summarised three criteria: extreme aloneness, failure to use language for purposes of communication, and insistence on sameness, as defining infantile autism (Knobloch and Pasamanick, 1975). He advised against including these distinct characteristics into the broader category of childhood schizophrenia, emphasising the need to recognise them as characterising a unique childhood disorder.

In 1944 Hans Asperger, an Austrian paediatrician, published an article in German describing a syndrome paralleling infantile autism which he termed, 'autistic psychopathy' (Lyons and Fitzgerald, 2007). This term denotes 'a shutting off of relations between the self and the outside world' (Frith, 1991) (p.39). Asperger recognised the similarities between the children he described and those described by Kanner, but contrary to Kanner he believed the disorder had a genetic aetiology with a lifelong, persistent impairment. The children Asperger wrote about lacked empathy and had great difficulty forming relationships with other children. They did not display delayed language and many had extensive knowledge in a very specific area of interest, although they were not able to engage in reciprocal conversation. Asperger referred to them as 'little professors' (Volkmar et al., 1998) (p.459).

To early clinicians and researchers autism was linked to schizophrenia (Rapoport et al., 2009). Working within the prevailing ego psychology paradigm of the time, it was thought that the infant's psychic development was dependent on the mother's degree of empathy and attunement to her infant (Astis, 1997). Kanner (1943, 1949) described the parents of the

children he diagnosed with infantile autism as cold, intelligent, detached and emotionally unresponsive. Thus, it was believed that as a result of the poor mother-child relationship the child's ego development was inhibited with childhood psychosis ensuing (Hollin, 2016). Bruno Bettelheim (1967), an American child psychologist, extended this ideology with his theory that children develop autism as a result of cold and uncaring mothers. He explained that traumatised, unloved children in the care of 'refrigerator mothers' were more likely to become autistic (Bettelheim, 1967). The stigmatising mark of a 'refrigerator mother' was universally noted. In the 1960s the gold standard of treatment was psychoanalysis for the child and his/her parents with the expectation of uncovering unconscious motives and repressed childhood conflicts to enable reconstruction of the child's intrinsic personality. The objective of psychoanalysis was to cure the child and restore the natural development process. The impact of the blame and stigma attached to parents of children with ASD lingered long after the medical and scientific world had moved on to more grounded understanding and interventions for autism. For the oldest parents participating in the current research, such impressions may have had lasting implications for current and future care decisions.

#### **Autism as a neurobiological disorder**

The negative perceptions of mothers of children with ASD were criticised for the lack of an evidence base. A seminal study by Creak and Ini (1960) challenged the concept of a parental personality stereotype as they found no evidence to support it in a review of 100 cases (Creak, 1963). This was followed by further studies which corroborated their work, finding no such personality type among mothers with autistic children (Kolvin et al., 1971, Pitfield and Oppenheim, 1964, Rutter and Bartak, 1971). Researchers also found no confirmation of maternal detachment among the mothers of children with ASD (Pitfield and Oppenheim, 1964, Rutter and Bartak, 1971). These studies set in motion the search for an organic aetiology.

Bernard Rimland (1964) was one of the first to propose a biological basis for the disorder. Rimland, an American psychologist and a parent of a son with autism refuted that either he or his wife were 'refrigerator parents'. He stressed that autism was a biological disorder and not an emotional illness. However, it was not until three decades later that research has been able to show that children with ASD have unusual brain growth patterns (Akshoomoff et al.,



2004, Courchesne et al., 2001); anatomical and metabolic abnormalities (McAlonan et al., 2005, Schifter et al., 1994) and neurotransmitter system changes (Blatt et al., 2001, Murphy et al., 2006).

Although many regions of the brain have been implicated and researched as its genesis, a definitive region as the source of autistic behaviours remains unidentified. The link between observed brain pathology and behavioural and functional deficits experienced by people with autism continues to elude researchers. However, research has provided decisive evidence for the recognition of autism as an organic brain disorder. Given the complexity and variability of presenting features in people with autism, it is hypothesised that many brain areas may be involved in the disorder and that although initial structural alterations may occur in prenatal brain development, other neuroanatomical changes are also likely to occur across the life course (Geschwind, 2008).

#### **Autism as a genetic disorder**

In addition to exploring a biological basis for autism, researchers have also investigated a genetic link. For example, a study of 11 monozygotic (MZ) and 10 dizygotic (DZ) twins, (where at least one cotwin met the criteria for autism) showed none of the dizygotic twins concordant for autism, but 36 percent of the monozygotic twins were (Folstein and Rutter, 1977). Similar concordance rates have been confirmed in subsequent twin studies (Bailey et al., 1995, Le Couteur et al., 1996, Mason-Brothers et al., 1985). Even in those studies where the co-twin did not meet diagnostic criteria for autism subjects often displayed similar symptoms of autism, including language impairments and social deficits. This is suggestive of a milder form of autism and infers the possibility of a broader phenotype (that is, the observable characteristics or traits that result from genetic expression). Twin research strongly suggests that genetic factors play a predominant role in the aetiology of autism.

Moreover, the frequency with which siblings exhibited the autism phenotype was consistent across a number of studies (Smalley, 1988). The sibling recurrence rate of ASD is almost 20% greater when an older sibling has been diagnosed with ASD (Ozonoff et al., 2011). In another study, parents with more than one child diagnosed with autism were compared with parents of a child with Down syndrome on social, communication and behavioural aspects (Piven et

al., 1997). The authors found that parents with a child diagnosed with autism (in contrast with a child diagnosed with Down syndrome) had significantly higher deficits in social skills and relationships, cognitive performance, language delays and speech limitations. Findings from later studies also support the idea of a broader autism phenotype (BAP) in the parents with similar disabilities identified in their children (Piven, 2001). Thus, the potential for the broader phenotype of autism might have implications for the ability of siblings to assume support responsibilities for their brother or sister with autism in adulthood.

#### **Autism as a result of environmental factors**

Converging evidence from twin, sibling and family studies has confirmed with certainty that genetics plays a role in the aetiology of autism, but not exclusively. Thus research has continued to investigate potential non-genetic environmental factors including early exposures to viral illness, toxic chemicals and vaccines.

In 1971 following an epidemic of rubella in the United States, Chess studied the behavioural characteristics of 243 toddlers who had been affected in utero by the disease (Chess, 1971). Ten children were diagnosed with autism and another 8 fell within the criteria for the broader phenotype. The high prevalence rate of autism found in these children led Chess to suspect an association between autism and prenatal exposure to the rubella virus (Chess, 1971). However, others have found no relationship between prenatal exposure to rubella and autism (Libbey et al., 2005).

As the first trimester of pregnancy is critical for the developing foetus some researchers have proposed that foetal exposure to toxic chemicals, viral infections and some medications may be associated with an increased incidence of autism (Hertz-Picciotto et al., 2006, Landrigan, 2010, Libbey et al., 2005). Other researchers have also suggested that foetal exposure to maternal infections (Libbey et al., 2005) and maternal immune system disorders (Currenti, 2010) may also be responsible.

The age of onset of autism is correlated with the timing of early childhood vaccinations; this led some parents and researchers to hypothesise an association. In particular, the measles-mumps-rubella (MMR) vaccine was thought to be associated with autism (Wakefield et al.,

1998). However, further studies have found no evidence to suggest that a link between childhood vaccines and autism exists (Honda et al., 2005, Taylor et al., 2002). Twelve years later the initial paper that implied a link between vaccinations and autism was retracted from the journal in which it was published (Eggertson, 2010).

Yet, despite extensive research efforts the specific cause and risk factors of autism remain elusive. Advances in understanding autism have progressed and extensive research continues. No longer considered a psychiatric disorder, that is the result of a poor mother-child relationship and arrested ego development, autism is now defined as a complex neurodevelopmental disorder with genetic and environmental causal factors (Currenti, 2010). In addition, the diagnostic parameters of autism have changed over time and are discussed next.

### **An overview of diagnosis**

At the outset, autism was considered a rare psychiatric condition with a poor outcome by the medical profession and as a social embarrassment by the general public. Until the mid-1960s, autism was not differentiated from mental retardation and/or mental illness with institutionalisation often thought to be the best solution (Bettelheim, 1967, Hollin, 2016, Rutter, 1974). In 'The Autism Matrix' (2013) author Gil Eyal posits that the deinstitutionalisation of mental retardation in the mid-1970s created a radical transformation in societal conduct and views of childhood developmental disorders. The shift to community care, and the protracted social awareness of autism, may be relevant to the adults and parents who participate in this research study. These adults with autism and their families have witnessed and experienced diverse changes in the social and historical environments related to autism over their life course.

There are currently no medical tests available to detect the presence of ASD; it is identified by a pattern of abnormal behavioural characteristics. The diagnosis of ASD indicates that qualitative impairments in communication, social skills, and range of interests and activities exist. Thus the diagnosis is based on the observations of the presence or absence of specific behaviours. The defining behavioural criteria used to denote a diagnosis of ASD have been modified over time. Diagnostic criteria have broadened, reflecting changes in the

understanding of ASD. Acknowledging these changes is relevant to the current context of ASD and its implications for adults diagnosed in the mid-twentieth century, and those who were more recently diagnosed. The diagnosis of autism is based on observing behavioural abnormalities which occur in varying degrees of severity combined with a concise medical history. As such, a cursory overview of changes over time to diagnostic criteria will assist in positioning current diagnosis and diagnostic tools.

Following World War II the World Health Organization (WHO) included a section for mental health disorders for the first time in the sixth edition of International Classification of Diseases (ICD). The ICD is the standard diagnostic tool for epidemiology, health management and clinical purposes used universally within the medical and health care professions (World Health Organization, 1992). In 1952 the American Psychiatric Association Committee on Nomenclature and Statistics published the first edition of the Diagnostic and Statistical Manual: Mental Disorders (DSM-I), the standard classification of mental disorders used by mental health professionals in the United States. The DSM outlines three major components for listed mental disorders: diagnostic classification, diagnostic criteria sets, and descriptive text. A brief historical review of these gold standard manuals, as they are used in the diagnosis of mental disorder, helps to highlight modifications to the diagnostic criteria for autism made over time. This recognition is significant to older adults with autism who received a diagnosis using a narrower set of criteria than those more recently diagnosed and compared to younger adults who received a diagnosis in childhood.

Historical records show the evolving terminology used for autism, including childhood schizophrenia, infantile autism, and autism spectrum disorder or condition, as well as the modifications to the defining criteria. Although Kanner classified autism as a distinctive disorder in 1943, it was not included in the first DSM or in the edition of the ICD at that time. Thus, children who exhibited autistic-like symptoms were diagnosed under the classification of schizophrenic reaction, childhood type label. In response, Eisenberg and Kanner (1956) defined a narrow framework for the diagnosis of infantile autism consisting of two categorical indicators: a profound lack of affective contact and repetitive, ritualistic behaviour of an elaborate kind. They did not include any age parameters and the diagnosis mainly identified severe forms of autism (Eisenberg and Kanner, 1956). Infantile Autism

Psychosis was included in the 1978 ICD-9 manual, and revised in name and discerning criteria to Childhood Autism PDD (Pervasive Developmental Disorder) in 1991 in the ICD-10 (World Health Organization, 1992). The first identification of autism in the American mental health manual was in the 1980, DSM III as Infantile Autism PDD. In the 1987 revised edition, DSM III R, its terminology was changed to Autistic Disorder PDD (Cohen et al., 1987, Filipek et al., 1999).

In the DSM III (1980) there were six characteristics listed and each of these had to be consistent in presentation to confirm a diagnosis of infantile autism. Advances in the health sciences including the recognition that the disabilities associated with autism were lifelong, saw the descriptor infantile deleted and changed to autistic disorder in 1987. Wing's 1981 seminal article popularised the research of Hans Asperger and introduced the term "Asperger syndrome" to a wider audience (Wing, 1981). The wide range in symptom severity and unique individual symptom combinations she observed in her patients prompted Wing to propose autism as a spectrum disorder. In 1992 the ICD-10 included a broader range of categories of autism. Likewise, the DSM IV (1994) reflected the extensive body of research on autism by widening the diagnostic criteria from categories to a spectrum with the inclusion of Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (Wing et al., 2011, Filipek et al., 1999). Specific social interaction, communication and behavioural deficits outlined in these manuals must be present before the diagnosis of autism is given. The publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in May 2013, based on current research and clinical experience and once again the diagnostic criteria for autism were modified.

Currently, the diagnosis is called Autism Spectrum Disorder (ASD). The sub diagnoses of Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Disintegrative Disorder have been reorganised into two categories capturing: 1) social communication/interaction, and 2) restricted and repetitive behaviours (Wing et al., 2011, Hyman, 2013). Over time, all the revisions detailed in these manuals have reflected progress in health sciences with the intention of providing more specific, reliable and valid diagnostic criteria for autism. Diagnosis is based on observations or reports of current

behavioural symptoms, as well as on an in depth developmental and behavioural history. Two diagnostic tools used in research and clinical practice to confirm diagnosis are the Autism Diagnostic Interview-Revised Edition (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS).

The ADI-R is an interview, generally with the mother, which includes a developmental history and reports of current behaviour. It focuses on three functional domains: language/communication, reciprocal social interactions, and restricted/repetitive behaviours and interests (Lord et al., 2014). The ADI-R provides categorical results which can be used to support a diagnosis of ASD and to determine the individual's clinical needs. The ADI-R has proven reliability and validity and is very effective in differentiating ASD from other developmental disorders and in assessing syndrome boundaries (Lord et al., 1994). The ADI-R is considered the “gold standard” diagnostic instrument in autism research, and is itself research-derived (Ozonoff et al., 2005).

The ADOS is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) for individuals suspected of having ASD or other pervasive developmental disorders (Lord et al., 2014). It consists of standardised activities that allow the examiner to observe the occurrence or non-occurrence of behaviours that have been identified as important to the diagnosis of ASD and other pervasive developmental disorders across developmental levels and chronological ages (Lord et al., 2000). Structured activities and materials, as well as less structured interactions, provide standardised contexts in which social, communicative and other behaviours are observed. The participant's response to each activity is recorded, rated and used to formulate a diagnosis. The ADI-R and ADOS can be used to assess both children and adults.

Although diagnostic alterations through the years aimed to define more clearly and specifically the parameters of autism to help clinicians in the diagnosis of the disorder, individuals who received a diagnosis in the 1960s or 1970s met very different diagnostic criteria than those diagnosed in the 1990s or later. However, the diagnostic criteria for autism are not the only changes through history. Changes over time in social awareness and

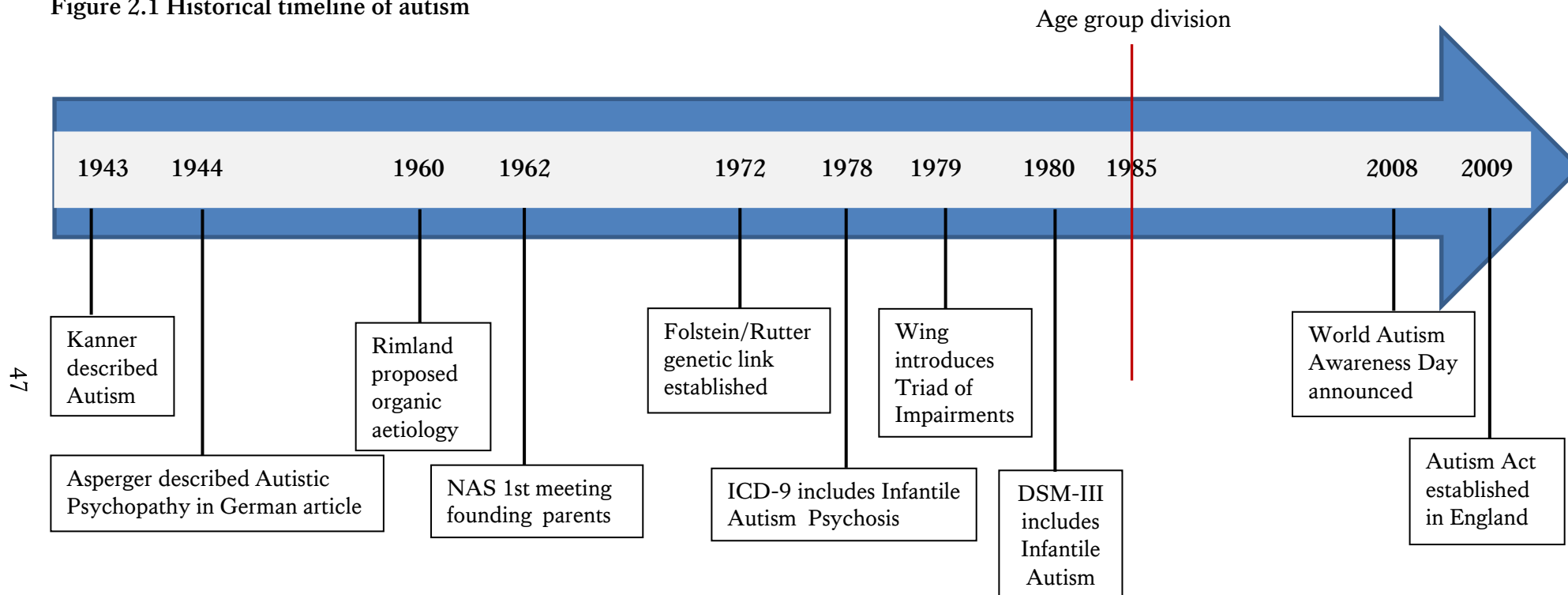
supportive services are also important and relevant to participants in this research. They are described next.

### **A historical overview of the social context of autism**

The social environment is a fluid context that changes over time. It contains the individual, family, community and related social networks, incorporated within the wider social structure and institutions in which they live. The social context includes the social care and support that an individual receives. Social care covers a broad range of services and in the UK is defined as the provision of social work, personal care, protection or social support services to children or adults in need or at risk (National Health Service England, 2012). Social services may include: health care, home care, and community support (National Health Service England, 2012). It encompasses help for people with disabilities, informational and advisory services, advocacy and support for carers. The need for support and services, meaningful and accurate information and acceptance is great in families with ASD. Parenting a child with ASD confers heightened levels of stress and unique challenges (Bristol and Schopler, 1984, Bromley et al., 2004, Dumas et al., 1991, Estes et al., 2009, McStay et al., 2013, Nealy et al., 2012). Adequate and appropriate social support has been demonstrated to reduce parental stress and improve wellbeing for parents of children with ASD (Nealy et al., 2012, Siklos and Kerns, 2006). Additionally over the longer term, it may help minimise the general level of disability associated with ASD.

The social context in which individuals live and interact influences their actions, thoughts, and feelings, and reciprocally their behaviours can impact on the social environment. Both person and environment can be understood only in terms of their relationship, in which each continually influences the other. Detailed information about the historical social environment for children with ASD and their families is limited. Yet, describing the historical social context and services of autism available when they were children may emphasize the life course experiences of today's adults with ASD and their families. Figure 2.1 illustrates key historical changes in the medical and social environment of autism since it was first described by Kanner. These changes over time are outlined and the social environment described next.

Figure 2.1 Historical timeline of autism





### 1943-1960

In this time period parents who received a diagnosis of autism for their children may have numbered a few among many who for numerous reasons had not. Undefined diagnostic criteria compounded autism's precarious acceptance within the medical and scientific community and limited its understanding and awareness (Wing, 1985). With so few people given a diagnosis, many people with autism may have been 'hidden' within data records under different diagnoses. Furthermore, many of these children in the UK were classed as "hopeless" with custodial care in a mental subnormal hospital or institution prescribed (Lotter, 1974). The wider social awareness of autism was negligible.

Parents during the 1940s and 1950s were virtually isolated with few resources or information to help them in raising their children with autism. In, *Involuntary Strangers, Autism: The problems faced by parents*, Everard, (1980) presents her own experiences raising her son with autism who was born in 1952. She recounts feeling very alone, receiving no real help or encouragement when he was a child. Parents at that time received little support from formal services and had no source to learn from other parents with a child with autism. Additionally, during this period, many children with autism may have been considered uneducable and excluded from the public school system based on their IQ scores. Children with learning difficulties did not have a right to an education. Everard explained,

At five, the age that children must enter school, the local authority acknowledged his existence by asking me to take him for an IQ test at the clinic. In 1957 mentally handicapped children were sorted into those who were considered 'educable' that is, those with an IQ of 50 or above and 'ineducable' those who had an IQ below 50 (p43).

Research has described how a social worker's knowledge of autism may have influenced assessment and service provision; there was also confusion about some key aspects of autism among study participants (Preece and Jordan, 2007). For social workers in this era the very small population diagnosed and inadequate knowledge and/or experience with autism among professionals may have further compounded their interactions with families with children with autism. Searching for emotional causes, the medical establishment lay blame on the parents for their child's autism during this time (Bettelheim, 1967). Parents of children with autism in this time period had few options for support and care from which to choose. The

family may have become self-reliant, with family roles and responsibilities for care provision an inherent duty.

### 1960s and 1970s

Early research had characterised the parents of children with autism as cold and insensitive and blamed them, particularly the mothers as causing their child's autism. Research in this time period dismissed the stereotyped parental characteristics as psychologically damaging and causal of autistic children (Creak, 1963, Kolvin et al., 1971, Pitfield and Oppenheim, 1964, Rutter and Bartak, 1971). However, parental psychogenic blame was redefined by some behavioural psychologists as parental behavioural blame, such that poor parenting skills were reinforcing the disruptive behaviour of children with autism (Ferster, 1961, Rutter, 1968). Parental blame may have been perceived as a double edged sword: on the one hand a parent was culpable of their child's disorder while on the other, if a parent was the cause, there was the possibility of a therapeutic cure. When parents were believed to have caused their child's autism they were scrutinised, treated, researched and stigmatised. Fraknoi and Ruttenberg (1971) reported that mothers were studied intensively with the aim of understanding and modifying their attitudes and behaviours towards their autistic child. Researchers and professionals indirectly stigmatised parents of autistic children (Gray, 1993). The impact of the blame and stigma ascribed to parents of children with autism may have limited the service provisions offered and available to them. The stigma of autism lingered long after the medical and scientific world had acquired a more grounded understanding of the disorder. For older parents of an adult with autism today such impressions may have lasting implications for current and future support decisions.

In the UK, parents of children with autism seeking support and sharing information became an organised unit in 1962, which became the National Autistic Society (NAS). The mission of the founding parents of the NAS was to raise public awareness of autism and provide information and advice for parents. The NAS lobbied to include autism as a developmental disability added into the Education (Handicapped Children) Act in 1970, which enabled children with autism access to a free and appropriate public education. Along with reports of effective training and teaching methods for teachers and nurses, parents were beginning to be considered as partners in the helping process for their children and taught to assume a role of

co-therapist in their children's learning and behaviour modification programs (Koegel et al., 1978, Schopler and Reichler, 1971).

### 1980s to 2000

The development of community care and the closure of most long-stay hospitals, combined with the shift in private or commercial social care services, placed social workers in new roles as gatekeepers of local authority funding and as care managers with responsibilities for assessment, care planning and review. The separation of children's and adults social services appears to have challenged continuity of care, although community learning disability teams and some transition services seemed able to span the child/adult divide in social work support. Autism was now understood to be a neuro-developmental disability. Lorna Wing (1993) introduced the concept of autism as a spectrum which produces a wide range of cognitive and neurologic impairments. The themes of the extraordinary stress experienced by many parents and siblings who live with and care for an autistic child continued to be supported by growing evidence about the stresses of caring more generally. Social support was shown to lower stress levels in parents of children with autism (Bristol, 1987), but was in short supply. Unmet service needs, including information and supportive care, were shown to contribute to carer burden (Heller and Factor, 1993).

Public awareness of autism heightened and autism research increased dramatically in this time frame. The popularity of the film 'Rain Man' (1988), about an autistic savant man, helped propelled autism into the general public's purview. The NAS continued to advance social awareness, encourage research, and press for government initiatives, services and support for people with autism and their families. They opened new schools and residential communities for individuals with autism, NAS offices in Wales and Scotland and a national help line to extend the reach of information, advice and support to families. The NHS and Community Care Act 1990 extended the responsibility of local authorities to perform individual assessments for the need of community care services; included under this directive were individuals and families with autism. The NAS pressed to have autism included in the Developmental Disability Act (1995) to authorise services and support for children with ASD and their families. Furthermore, the Carers Act 1995 established guidelines under which a person providing substantial care on a regular basis for someone could be entitled to an

assessment of their needs as a carer and have services provided. Parents providing care for their adult children with autism may have met these guidelines for assessment, recognising and having their individual needs met.

#### **2000 to date**

The social care environment, legislation and policies in the UK of this time period form the platform on which this research is established and will be described in detail in the subsequent chapter: Describing the current context for adults with ASD.

Through advocacy efforts parent associations have provided the impetus for policy change, encouraged and funded scientific research, raised public awareness and provided information, reference and support for millions of families with children with ASD. Furthermore, whereas early advocates were parents, practitioners and researchers campaigning for people with autism, recent organizations such as Autism Network International, the Autistic Self-Advocacy Network and the Global and Regional Asperger Syndrome Partnership have been established by, and for, people with ASD. Thus recently a growing number of autistic people have begun to express and share their perspectives and concerns and take an active role in public policy, research, service-delivery and media discussions that impact their lives. Through the efforts, actions and voices of individuals and groups advocating for change, coupled with advances in knowledge, the social environment of autism today is very different from what it was 60 years ago. However, despite great strides for services, recognition and inclusion for children with ASD, health and social services and supports for adults with ASD remain inadequate despite recent NICE Adults with Autism guidelines (Wilson et al., 2013). Programs for social learning, leisure activities and skills for daily living are area specific and may not be available in the local area where an adult with ASD lives. Few autism-specific medical services exist for adults with ASD in the UK. Gaps seem to exist between social policy mandates and service implementation.

## Chapter summary

Medicalisation is the process by which a human condition or problem comes to be defined and treated as a medical condition, which requires medical study, diagnosis, prevention, and treatment (Lowenberg and Davis, 1994). As discussed, autism became known as a distinct disorder in the mid-twentieth century. A medical diagnosis provides the direction of social resources (Valentine, 2010). The medicalisation of autism identifies it as a ‘problem’ and people with the ‘problem’ in need of certain treatment and support. Over time, the limits of the medicalised condition of autism have become wider, with a multitude of therapeutic interventions and a wide range of social support developed (Lai and Baron-Cohen, 2015). The distinction of the limitations associated with a diagnosis of autism necessitated the eventual establishment of formal services, particularly educational support throughout childhood. However, the infrastructure of childhood services and support for ASD has not been extended to continue across the life course into adulthood and old age (Dillenburger and McKerr, 2009, Lai and Baron-Cohen, 2015).

Relevant to this study, participating older parents may have raised their adult children in relative isolation without the aid of social services. They may well remember the limitations of the past and still be wary of professionals and social services. Some older adults with ASD may not have experienced effective educational and social skills teaching or employment support, while younger adults with ASD may have experienced a wide range of supportive resources and intensive interventions over their life course. An appreciation of the social context in which they grew up may provide an understanding of their present situation, decisions and future expectations. The next chapter provides a more detailed description of the current context for adults with ASD.

### **Chapter 3: Describing the current context for adults with ASD**

This chapter outlines the current context of community care and support services for adults with ASD in the UK. It begins with a description of ASD as a disability, followed by a brief explanation of the medical and social models of disability to create an awareness of the present sociopolitical perspective of disability. Policies, resources and services are influenced by prevailing perspectives. Subsequently, the support needs of adults with ASD and their family members are considered. Additionally, the chapter includes a delineation of the existing social policies and service structure responsibilities relevant to adults with ASD. A comprehensive picture of the current social political context for adults with ASD in the UK will help frame the environment within which this research was conducted.

#### **ASD as a disability**

An explanation of the broader societal perspective of disability is helpful for an appreciation of the current social political environment for adults with ASD today. Disability is a difficult concept to define. It has been defined by functional limitations in a person's capacity to perform activities of daily living (Grönvik, 2009). This way of defining disability stems from a medical understanding of disability. Judicial and administrative definitions of disability are used to make decisions to meet the objectives and social context of an organization (Haber, 1988). For example, this definition is used by authorities that evaluate disability benefit programs and eligibility criteria. Additionally disability may be defined as a subjective measure in which an individual conceives of her/himself as, or as not, disabled (Grönvik, 2009). A brief discussion of neurodiversity and the neurodiversity movement highlights this perspective. A person is considered disabled under the Equality Act if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to undertake normal daily activities (Act, 2010).

ASD is predominantly a lifelong disorder that causes substantial impairment in communication and social interactions which may affect daily activity abilities including employment, transportation use, personal care, safety, and relationships. In addition, co-

occurring intellectual disabilities and psychiatric disorders as discussed in Chapter 1, may further effect an individual's ability to carry out daily activities and social engagement. ASD may include a strict need for routines and sameness and makes it hard to cope with changes and surprises (Militeri et al., 2002). As described in Chapter 1, autistic individuals may also experience sensory issues which can cause many difficulties and limitations (Ben-Sasson et al., 2009), and they may process information differently, which can impair learning and heighten exploitation and safety risks (Kana et al., 2006). These challenges enumerate some of the grounds on which ASD may fit the functional or legislative definition of a disability. While many adults with ASD may clearly meet a definition of disability, some may not consider themselves disabled and prefer the more neutral, value-free term of 'difference' to the label of disability (Baron-Cohen, 2000).

## **Models of disability**

Models of disability are tools for conceptualizing impairment and provide a basis upon which government and society devise strategies for meeting the needs of disabled people (Barnes and Mercer, 2004). A number of models of disability have been developed. The two most frequently considered are the 'medical' and 'social' models. The medical model views disability and impairments as an individual 'problem'. An impairment is a problem in body function or structure (World Health Organization, 2014). It is a bodily state, characterised by a malfunction of the physical and/or cognitive abilities of the individual. Under the medical model, impairments or differences should be fixed or treated with medical interventions (Crow, 1996). It focuses on identifying what is physically or cognitively 'wrong' with the person, relative to 'normal' functioning and how it can be remedied (Shakespeare and Watson, 2001). In the medical model the impairment, diagnosis, label and treatment are emphasised with decisions and control being managed by professionals (Barnes and Mercer, 2004, Kapp et al., 2013). The ideology of the medical model is considered outdated by advocates of disability rights who tend to subscribe to the social model (Shakespeare and Watson, 2001).

The social model of disability, in contrast, sees the 'problem' as being on a societal level; the idea that society creates disabling barriers for people (Watson, 2007). These barriers may encompass physical limitations in the built environment, inflexible policies, practices or

procedures through the way in which society is organised, and also through social attitudes, including prejudice, stereotype and stigma that restrict equal opportunities, disabling people with impairments (The Office for Disability Issues, 2010). The aims of the social model are greater social inclusion, participation and choices for people with disabilities (Shakespeare and Watson, 2001). It focuses on identifying individual strengths and needs and empowering the individual to pursue his or her own goals. The social model does not minimise or disregard an individual's functional limitations; however, it views the loss of opportunities resulting from direct and indirect social barriers as the main issue.

While the medical model is slanted towards medicalising ASD, the social model may be too heavily weighted on social oppression of disability. There is now acknowledgement in the social disability model that society cannot 'fix' everything. Undeniably the impairments of ASD have a direct causal effect on the daily restrictions of activity for autistic adults. Furthermore, the way in which a disability is most commonly perceived has a reflective impact on the manner in which social policies are designed, resources are distributed and services provided. In the medical model, medical cure and/or treatment is viewed as the main issue with policy directed at modifying or reforming healthcare, and resources justified for procedures, technologies and research. More resources remain concentrated on impairment-related research and intervention than on social change for the inclusion of adults with ASD (Crow, 1996). However policy and legislation in the UK has begun to address these issues and will be described subsequently.

### **Current issues of neurodiversity and the neurodiversity movement**

Although characteristics and limitations associated with autism may meet the definition of a disability, some autistic individuals consider autism a natural variation in neurological functioning rather than a neurological disability (Baker, 2006; Jaarsma and Welin, 2012). The term 'neurodiversity' was coined by Judy Singer, a sociologist diagnosed with Asperger's Syndrome (Singer, J. 1999). The neurodiversity paradigm introduced by Nick Walker is a set of beliefs that all minds are equal in value with none superior to another (Walker, 2012). This contrasts with the medical model of disability that presents an ideal 'normal', healthy status with differences considered to be deficient or defective. Thus it is important to position



neurodiversity as a concept within the existing discourse surrounding conceptions of disability.

The neurodiversity movement was developed in the 1990s by self-advocates through online interactions (Ortega, 2009; Singer, 1999). It comprises social advocates and activists who support the neurodiversity paradigm and the civil rights of those diagnosed with neurological or neurodevelopmental disorders (Ortega, F. 2009). The ultimate goal of the neurodiversity movement is establishing an autistic community that can exercise control over the social, medical, and judicial discourses that surround their bodies. Neurodiversity activists present a counter-narrative to the hegemonic medical model discourse circumscribing autistic existence. The dominant organising principle of the neurodiversity movement is that autism and other neurological differences are exactly that: differences, rather than deficits or flaws (Brownlow, 2010; Nicolaidis, 2012; Ne'eman, 2010). Neurodiversity activists generally reject a medical model of autism, preferring to conceive of autism as “a way of being” (Barry, 2012, Kapp et al, 2013).

Autistic self-advocates argue that autism is analogous to race or gender as an identity category, and that many of the medical interventions and paradigms of thought regarding autism are illogical or actively harmful under that paradigm (Sinclair, 1999; Barry, 2012; Ne'eman, 2010; Nicolaidis, 2012). This entails a critique of care practices, especially those that focus on “normalising” an autistic person, rather than enabling them to exist without having to conceal or eliminate autistic modes of presentation (e.g. self-stimulating behaviour, interests that are commonly understood to border on fixation or obsession, non-verbal communication). Neurodiversity activists consider applied behaviour analysis (ABA), the method of behavioural modification training developed and popularised by Lovaas, as a key example and offence of normalising practice (Barry, 2012). ABA is a therapeutic intervention that systematically applies principles of operant learning to build behavioural repetition in both structured and unstructured situations (Peters-Scheffer et al. 2011). Tasks are broken down into small discrete steps and taught in a systematic and precise way called discrete trial training (Spreckley and Boyd, 2009). The use of ABA for children with autism has reported gains in communicative language, social interactions, academic performance, daily living skills and reductions in challenging behaviours (Grey et al. 2005; Virues-Ortega, 2010).

A significant rhetorical struggle of the neurodiversity movement is one against person-first language (person with autism), which autistic neurodiversity advocates consider incongruous to their identities, such that autism forms a part of, and is inseparable from, their personhood (Sinclair, 1999; Owren and Stenhammer, 2013). The term 'person with autism' is allied with the medical model, suggesting there is a 'normal' person imprisoned by autism and in need of a cure (Fenton and Krahn, 2007). In alignment with the social model of disability, the neurodiversity movement advocates rather than changing the individual, society should accommodate and support autistic persons, as they are, in ways that would enable them to live constructively (Lawson, 2009).

However, there is also contentious debate over whether autistic self-advocates and neurodiversity proponents are qualified to articulate and address the broad range of issues and needs faced by autistic people across the spectrum, with others contending that parents, siblings, and professionals are indeed better positioned to do so (Fein, 2012). Moreover, it is not just a matter of IQ level. Many higher-functioning autistic adults have unseen disabilities that may impair sound decision-making or the ability to perform daily skills placing them at a great risk of harm. Additionally, the impact of depression, anxiety, fatigue, and other co-morbid disorders renders otherwise capable autistic people dysfunctional. Nor is the neurodiversity movement accepted by all autistics (Kapp et al 2012). The concerns of opponents to the neurodiversity movement is that they trivialise the disabling aspects of autism (White, 2016). It is essential to recognise and understand the diverse range of needs of adults with autism and the challenges they may face in everyday life. As such, services must provide flexible and individualised support to meet the needs of adults across the autism spectrum to ensure their safety and wellbeing. This incorporates formal and informal support, as well as the acceptance of difference by making reasonable adjustments to individual needs, sensitivities, preferences and communication abilities. Subsequently, an overview in the developments in autism legislation in England provides a link to autism and autism-related policies to highlight support and service availability for adults with autism and their family members.

## Overview of policy and legislation in the England affecting people with ASD

Society's awareness of ASD is increasing, yet remains low with regards to adults with ASD. This makes genuine inclusion difficult to achieve as adjustments from others are often required to enable full participation in society. Policy and legislation have been developed with the aim of improving services to meet the needs of adults with ASD and to generate a societal culture shift to advocate equality. A brief chronological overview of current key policy and legislation in the UK relevant for people with ASD and specifically for adults with ASD will highlight governmental developments and the contemporary social context (See Table 3.1).

**Table 3.1: Current ASD relevant policy and legislation in England**

Policies and Legislation in England		
Autism Specific		Non-Autism Specific
	2001	White Paper Valuing People: A New Strategy for Learning Disability for the 21st Century
Better Services for People with an Autistic Spectrum Disorder	2006	
	2007	Putting People First
	2008	The Independent Living Strategy
	2008	Lifetime Homes, Lifetime Neighbourhoods
Autism Act	2009	
Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England	2010	
	2013-2016	Raising Standards, Putting People First: Our Strategy
Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum	2012	
	2014	The Care and Support Act

### ASD specific policies and legislation in England

In 2006 the Department of Health issued, *Better Services for People with an Autistic Spectrum Disorder*, to clarify existing government policy and expectations for the delivery of public services for people with ASD at the local level (Department of Health, 2006). Subsequently recognition that people with ASD were ‘falling through gaps in services’ provided the momentum for the Autism Act (Department of Health, 2006, Loynes, 2001). The Autism Act 2009 made provision for the needs of adults with ASD, and was the first ever disability-specific legislation to be passed in the UK. The Autism Act required the Secretary of State for Health to publish an adult autism strategy and to issue associated statutory guidance for local authorities and National Health Service (NHS) bodies (Parliament, 2009).

In March 2010 the Government produced an adult autism strategy: “*Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England*.” This set out the strategy for meeting the needs of adults with ASD in England through the provision of relevant services by local authorities and the NHS (Department of Health, 2010a). It established a clear framework for all mainstream services across the public sector to work together to provide services for adults with ASD (Walsh and Hall, 2012). This included: increasing ASD awareness, training for staff working with people with ASD, improving access to a diagnosis and assessment, and increased service and support of people with ASD. Furthermore, in addition to improvements in public services, the strategy included requirements for mainstream services such as transportation, leisure and employment to adjust to and meet the needs of adults with ASD.

Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy followed in December, 2010 (Department of Health, 2010). Local authorities and NHS organisations need to abide by the guidance, and improve access to social care for adults with ASD. In 2011, the Department of Health published a best practice guidance to evaluate the progress of ‘*Fulfilling and Rewarding Lives: The Strategy for Adults with Autism*’ as a template to assist Local Authorities and NHS organisations and their partners to assess their achievements. It outlined seven quality outcomes, including better health and employment, appropriate accommodations, inclusion in planning and personalisation of care and satisfaction with local services (Department of Health, 2011). The

key ambitions involve the recognition of the number of adults with ASD in local communities, having established diagnostic pathways and the provision of appropriate accommodations by service personnel to meet the needs of adults with ASD.

Local autism partnership boards or similar organisations have been set up in order to implement the adult autism strategy, which says it is essential that adults with autism and parents/carers are involved in the development of local services. The partnership boards aim to bring together different organisations, services and stakeholders locally and set a clear direction for improved services, including health and social care. This includes programme development for training of health and social care professionals, as well as for Job Centre Disability Employment Advisers. The focus is on building communities that are more aware of, and accessible to, the needs of adults with ASD.

The *Autism Self-Assessment Framework* is a national exercise to look at the progress being made in implementing the Adult Autism Strategy. The self-assessment data offers an opportunity to compare local authority areas and develop standards. A baseline assessment of local authorities was carried out in 2011, with a follow up to monitor their progress in implementing the Autism Strategy in 2013. The Autism Self-Assessment Exercise 2014 was the third national exercise to look at the progress being made. Local authorities were asked to co-ordinate responses to key questions from their local autism partnership boards, different organisations, services and stakeholders (including adults with autism and their family members). Questions broadly covered the same areas as the 2013 exercise: planning, training, diagnosis, care and support, housing and accommodation, employment, and the Criminal Justice System. Additionally, the 2014 Autism Self-Assessment included a new section entitled 'Local Good Practice', which comprised questions about new initiatives and services councils or their residents considered successful. The responses submitted by 149 local authorities (out of 152) were analysed.

Care and support, followed by employment were areas favourably rated by the largest number of local authorities. Additionally, the majority rated themselves weak on housing and accommodation. The statutory guidance builds on progress made over the last five years and sets out expectations for local areas so they can continue to develop services and support in

ways that reflect the assessed needs and priorities of their communities. The guidance emphasises involvement and awareness within local communities, support for what people with autism need and want, and details actions to be taken forward. Through greater transparency the autism self-assessment framework also enables adults with autism, their families and carers, and autism representative groups to see what progress is being made. This can further assist in identifying areas where action is needed and give direction in planning improvements.

Recognising a wide variation in rates of identification and referral for diagnostic assessment of ASD in adults, the National Institute for Health and Care Excellence (NICE) established further guidelines for the diagnosis and management of ASD in adults (National Collaborating Centre for Mental Health, 2012). The NICE guideline, *Autism: Recognition, Referral, Diagnosis and Management of adults on the autism spectrum*, details general principles of care for personnel working with adults with ASD and their family members and guiding principles and appropriate diagnostic methods for an ASD assessment in adults. It also outlines best practice for identifying, implementing and monitoring appropriate interventions and supportive services for adults with ASD. Moreover, it specifies the need for assessment and interventions for families, partners and carers of adults with ASD.

#### **Current interventions for adults with ASD and their effectiveness**

There is no effective pharmacological treatment for the core symptoms of ASD and most therapeutic strategies focus on psychosocial and behavioural interventions (Gibbs, 2010). However, many adults with ASD receive pharmacotherapy for associated medical or mental health comorbidities and/or troublesome behaviour (Eaves and Ho, 2008). Although ASD is predominantly considered to be a lifelong disorder (American Psychiatric Association [APA] 2000; Howlin & Moss, 2012; Howlin, 2014; Seltzer et al. 2003; Shattuck et al. 2007), there is recent evidence to suggest that with effective childhood interventions and maturation noteworthy gains in symptom reduction are possible, with some individuals no longer meeting diagnostic criteria (Fein et al. 2013, Orinstein et al. 2014; Troyb et al. 2014). Early interventions, support services and accommodating communities have resulted in improved outcomes in adulthood (Renty & Roeyers, 2006; Farley et al. 2009)

The National Institute for Health and Care Excellence [NICE] Guidance on interventions for adults on the autism spectrum include: psychosocial interventions focusing on improving social interactions and leisure activities; life skills and behavioural management interventions; interventions in the development of decision making and personal safety skills; and supported employment interventions (Pilling et al. 2012). Because many of the difficulties associated with ASD persist into adulthood, psychosocial interventions that target communication, social interaction, and flexibility of thinking and behaviour may prove efficacious for adults with ASD. Additionally, in conjunction with psychosocial interventions NICE guidelines emphasise any biomedical or pharmaceutical interventions prescribed should be monitored and regularly reviewed by qualified and experienced professionals (NICE, 2017).

A recent systematic review of psychosocial interventions for adults with ASD included 13 studies (Bishop-Fitzpatrick et al. 2014). Bishop-Fitzpatrick and colleagues found more of these studies focused on social cognition training to improve the participant's ability to grasp social cues and improve social functioning, than applied behaviour analysis (ABA) which sought to train basic self-help skills or reduce challenging behaviours (Bishop-Fitzpatrick et al. 2014). Positive benefits in terms of social skills knowledge and communication and decreased stereotypic behaviours from these interventions were reported, although the maintenance of benefit varied between studies. Conversely, Matson and colleagues' (2012) review of the literature found ABA to be a highly effective treatment to teach adaptive living skills in areas including work, self-help, leisure, independent living and hygiene for people on the autism spectrum. Cognitive Behavioural Therapy (CBT) is frequently used to treat the symptoms of comorbid psychological conditions in adults with ASD (Spain et al, 2015). CBT is a talking therapy that focuses on the development of personal coping strategies by changing unhelpful thinking patterns (thoughts, beliefs, and attitudes), behaviours, and emotional regulation (Beck, 2011). A systematic review of CBT interventions for adults with ASD reported more empirical research is needed to assess its effectiveness (ibid). Additionally, a few community-based intervention programmes targeting employment and leisure programmes have shown considerable success, with participants reporting decreased stress and improved quality of life. (García-Villamizar and Hughes 2007; García-Villamizar and Dattilo 2010, Howlin & Moss, 2012; Matson, Hattier, and Belva, 2012).

However, unless adults with ASD are supported by intellectual disability or mental health services, most do not have access to specialist multi-disciplinary community based health and social care services, and intervention provision is both limited and inadequate (Howlin & Moss, 2012). Additionally, perhaps as a consequence of limited intervention support, the rate of medication use, particularly antipsychotics, antidepressants, and anticonvulsants, tends to be higher in adults with ASD than in children (Esbensen et al. 2009). More research and resources are needed to provide, and evaluate, effective interventions for adult with ASD.

#### **ASD relevant policies and legislation**

The UK government has created policies and established good practice guidelines related to the care and service provisions specifically for adults with ASD and each nation has developed their own specific autism legislation. Moreover, there are other non-autism specific policies that are relevant for adults with ASD which are described briefly. These include: the White Paper *Valuing People*, *Putting People First*, *Independent Living Strategy*, and *Lifetime Homes, Lifetime Neighbourhoods*. Additionally, policies that are pertinent to carers may also be of great significance to adults with ASD, including the *Care and Support Act* (2014).

Research reports on the prevalence rate of ASD and learning disability vary from 50-75% (Emerson and Baines, 2010, Matson and Shoemaker, 2009). Therefore, some adults with ASD may be included in policies and legislation relevant to people with learning disabilities. One such example is the White Paper *Valuing People: a New Strategy for Learning Disability for the 21st Century* published in 2001 by the UK government. It had four key principles: rights, choice, independence and inclusion (Department of Health, 2001). The White Paper acknowledged that people with learning disabilities are among the most vulnerable and socially excluded in society. The strategy emphasised the importance of collaboration between local councils, health services, voluntary organisations and most importantly people with learning disabilities and their carers. '*Valuing People*' focused throughout its content on the importance of being person-centred in health and social care service provision (Department of Health, 2001). Furthermore, it outlined a series of key initiatives designed to tackle the social exclusion and discrimination experienced by many people with learning disabilities and their families.



*Putting People First*, introduced in 2007 by HM Government was a shared vision and commitment to a fundamental transformation of public services. It described the vision for development of a personalised approach to the delivery of adult social care and set out a framework for cooperation between the Local Government Association (LGA), the Association of Directors of Adult Social Services (ADASS), the NHS and others (Department of Health, 2007). The changes would improve the services for older people, people with physical or learning disabilities and people recovering from mental illness, as well as the wider community. *Putting People First* required that all local authorities transition to a system of personal budgets for anyone eligible for adult social care support and to provide improved information, support and advocacy to anyone in need of services, whether eligible for funding or not (Department of Health, 2007). Adults with ASD would be included in this restructuring of adult social care services. However, the appropriateness of personalisation of control and choice for all service users through direct payments and personal budgets has received criticism with the possibility of making some service users more vulnerable (Glasby, 2014). This policy was more recently followed with the strategy, *Raising Standards, Putting People First: Our strategy for 2013 to 2016* which sets out further aims to improve and monitor adult care and services (Care Quality, 2013).

The *Independent Living Strategy*, 2008, was a five year cross-government strategic plan between the Department for Work and Pensions; Department of Transport; Department of Health; Department for Children, Schools and Families; Department of Innovations, Universities and Skills; and Communities and Local Government to review and improve the choice and control that disabled people have over how the support they need is provided and accessed. The aim of the strategy was to change the way in which support and services were delivered and experienced, by offering greater access to housing, education, employment, leisure and transport opportunities and participation in family and community life for people with disabilities (Office for Disability Issues, 2008). However, adults diagnosed with high functioning autism or Asperger's may not meet eligibility criteria for such disability services (Powell, 2002). The "high functioning" label comes with the assumption that they do not need much help. This can result in poor outcomes with severe repercussions, as often high

functioning adults with ASD may be too socially impaired to get and keep a job or live independently without support (Powell, 2002).

Furthermore, strategies such as *Lifetime Homes, Lifetime Neighbourhoods* (2008) that aim to meet the housing needs of the general ageing population may not be including the support needs of social inclusion and safety issues adults with ASD may experience, particularly post-parental support. Limitations in employment, housing and support services may diminish the opportunities for independence and choice for adults with ASD as they age. Adults with ASD can live in all types of housing depending on their support needs. Some may be suited to a residential care home, while others may prefer to live on their own and receive home support. Some adults with ASD may live completely independently. Housing needs may become a priority post-parental support.

The provision of care may change over time as needs change and/or because of wider contextual factors, such as deinstitutionalisation and policy changes (Larkin and Milne, 2014). There is a growth in the demand, intensity and duration of care necessary to support family members with long-term conditions (ibid). Yet, despite the introduction of a number of new policy initiatives, few carers receive an assessment of support need (Buckner and Yeandle, 2011) and most do not receive substantial help from formal services (Niblett, 2011). The Care and Support Act (2014) prioritises individual wellbeing, needs and goals for both the person needing care and the person providing it. It creates a consistent method for establishing eligibility to public care and support, and for the provision of information and services (Department of Health, 2014a). Local authorities now have a duty to provide carers with their own assessment of support needs. The Care and Support Act may be beneficial for parents, partners, and possibly adult siblings providing care and support for an adult family member with ASD. The 2014 Care Act brings recognition and rights to carers and places a duty on local authorities to assess and meet a carer's needs if they are deemed to require support.

### **Provision of services for adults with ASD in England**

In England, the services that adults with ASD need usually come under the responsibility of four government departments: the Department of Health; the Department for Children,

Schools and Families; the Department of Innovation, Universities and Skills; and the Department for Work and Pensions (National Audit Office, 2009). In addition, housing-related support provided through the Department for Communities and Local Government may also be utilised. Adults with ASD differ in their intellectual and functional impairments which require individual assessment and customised supportive services to meet their social, health and mental care needs. Furthermore, as with anyone the needs of adults with ASD may change with age. Multiple service cooperation across a wide range of local organisations, including health and social care, education, employment and housing services is necessary to meet the varied support needs of adults with ASD.

A broad range of services and support are offered for adults with ASD, but service availability and accessibility varies by location across England. The key services offered to autistic adults in England are: assessment and diagnosis; community care; self-directed support of care packages; home-based services; accommodation and housing; and employment support. There are numerous other services available to adults on the autism spectrum including: advocacy and advice services, day services, holiday services, and support groups and networks. Additionally, local support groups and networks throughout England provide a range of help. These include befriending/mentoring groups, social skills groups and local branches of national charities, such as the National Autistic Society.

However, the availability of services and support does not guarantee accessibility for all adults with ASD. Moreover, not all adults with ASD will want or need services or support. The law now entitles people who have care needs to an assessment to determine if they are eligible for support from social services. Yet, neither the Autism Act 2009, nor the Care Act 2014, state which social services team should complete the needs assessment for a person with ASD. While community learning disability health teams vary across England, a self-referral, family member or GP referral can be made to request an assessment in most areas. In many local authorities, the learning disabilities team have an IQ cut-off of 70. This means that if an adult with autism's IQ is 70 or over the learning disabilities team may refuse to assess them, and another social services team would have to carry out a needs assessment. There may be a local ASD/AS team, a mental health team or another adult social care team to fill this responsibility. Although a recent draft of a service model for commissioners of health and

social care services (2015) reported that everyone with a learning disability and/or autism should have access to integrated specialist multidisciplinary health and care support in their community, geographical variation exists in the availability of local ASD/AS teams, although they are becoming a growing resource (NHS England, 2015). An individual needs assessment is the way social services determine an autistic adult's needs and eligibility for support. The Care Act 2014, introduced an eligibility level that is the same across England. To be eligible for support from social services the individual's wellbeing must be significantly compromised by their inability to manage or maintain a number of activities of daily living. For example, managing and maintaining nutrition, personal hygiene, toileting, or safety. However, if the adult with ASD's needs do not meet eligibility criteria they will not receive care and support services.

### **Care and support needs of adults with ASD**

Although increasing research has investigated adult outcomes for individuals with ASD (Eaves and Ho, 2008, Howlin, 2000, Howlin et al., 2014; Howlin et al., 2004, Seltzer et al., 2004), little research has purposely explored the assortment of support needs adults with ASD and their family members require (D'Astous et al. 2016). Hare and colleagues (2004) explored the social care needs of family carers of adults with ASD, but did not investigate supportive needs from the perspective of adults with ASD. The key unmet needs that were reported by the carers included respite care, information and planning for the future (Hare et al., 2004). Other research has considered the vocational support needs of adults with ASD (Hendricks, 2010, Howlin et al., 2005); the transitional support needs from adolescence to adulthood (Hendricks and Wehman, 2009); residential service needs (Gerhardt and Lainer, 2011) and the impact of unmet needs on carer burden (Cadman et al., 2012). Limited information exists on the health care service use of adults with ASD (Bruder et al., 2012). Additionally, research to date on the special health care needs of those with ASD has focused on children and their access to quality health care (Krauss et al., 2003). As identified in Chapter 1, diagnostic, preventative practices, screenings, dental and mental health services may be some of the health care needs of adults with ASD (Bruder et al., 2012). Aggregating support needs across research, adults with ASD may need support with employment, higher education, social relationships, independent living, leisure activities, mental and physical health, financial assistance and adapting to change. Parents and family members may also

require support services such as respite, information, future care planning and personal health related care (Dillenburg and McKerr, 2014).

Adults with ASD may be eligible for a range of benefits including Disability Living Allowance (DLA), Personal Independence Payment (PIP), Employment and Support Allowance, Disabled Person's Tax Credit and Jobseeker's Allowance (National Health Service, 2012). Additionally the current reconfiguration of specialised, personalised health and social care provision may improve access to appropriate services beneficial for the outcome and wellbeing of adults with ASD (Social Care Institute for Excellence, 2013). This new emphasis of personalised service provision is aligned with the social model of disability, focusing on individual needs rather than diagnostic labels.

## **Chapter summary**

Current UK policies and legislation have made substantial strides in developing and sustaining social care values and principles of workforce orientations relating to adults with ASD. In accordance with the social model of disability they have developed agendas and guidelines for local authorities and NHS to enhance services, support and social inclusion for adults with ASD. These developments took place alongside changes in both the forms and structures of service provision for adults with ASD. Efforts directed at facilitating medical access, assessment and diagnosis of ASD for adults are aligned with the medical model of disability. However, the socio-political environment described may not reflect the social reality that people with ASD experience. Discrepancies in service availability and accessibility vary between communities and councils in the UK (Beresford et al., 2011). Moreover, adults with ASD have different abilities and support requirements with little known about the lived experiences and service needs they will require as they age.

The number of adults with ASD is a growing population. Many currently are still being supported by their parents. There is limited knowledge about the support needs adults with ASD currently receive and what they will need post parental care. The National Autistic Society's 2008 *I Exist* campaign reported that 63% of participating adults with ASD stated they do not have adequate support to meet their needs (Saeki and Powell, 2008). Adults with ASD experience a number of challenges in daily living that heighten the need for planned

future support. Furthermore, families have different needs, expectations, resources, values, and priorities, which must be appreciated and respected. The next chapter describes what is known about family relationships of adults with ASD and how support roles may change over time, to help form a basis of understanding of the participants in this study.

## Chapter 4: Adults with ASD and their families

Autism spectrum disorders present lifelong challenges for both the individual and their family (Rao et al. 2009). This chapter describes the informal support and relationships in families of an adult with autism. It explores the relationship and support provision of parents, siblings and partners of adults with autism. Role changes and family future support planning to meet the needs of an adult with autism are described from the various family members' perspectives. The potential impact of changing family demographics, and its significance to the aim of this research to identify family roles and relationships and long term support planning for adults with ASD, is discussed. The chapter concludes with an exploration of previous literature on family future support planning and identifies gaps in the literature.

Social and demographic changes have resulted in parents providing lifelong support and security for their children with ASD. The National Autism Society (NAS) campaign, 'I exist' (NAS, 2009), reported that 49 percent of adults with ASD in the United Kingdom (UK) live with, and are supported by, ageing family members. Given increasing life expectancy among individuals with a developmental disability, these adults with ASD are likely to outlive their parents (Burke et al., 2012, Heller et al., 2010). Yet, little research has addressed how prepared families and social services are for this inevitable transition of support. Have parents of adults with ASD made plans for the continuation of their support? What support services do adults with ASD require, and do siblings envision assuming the support responsibilities for their adult brother or sister with ASD? Recognising the current and anticipated future support needs of adults with ASD will help inform policy and services how best to respond to the growing population of these ageing adults. Without such foresight to guide planning, the availability and accessibility of services may be ill-equipped to manage this eventuality.

To date research and societal resources have largely focused on ASD in childhood (Barber, 2015, Hollin, 2016, Wright, 2013). While the Autism Strategy in the UK acknowledges the necessity of assessing needs among adults with ASD it does not address how services will meet these needs (Department of Health, 2014b). Unmet needs are likely to have an impact not only on the individuals with ASD but also on their families. Unmet service needs, including information and supportive care, have been shown to contribute to carer burden

(Cadman et al., 2012, Heller and Factor, 1993). Thus individuals with ASD and their family members require recognition and support services not only during childhood but across the lifespan.

### **Parents of adults with ASD**

Autistic adults require varying amounts of support and assistance, with families being the main care providers across the lifespan (Povey et al., 2011). The essential care and support ageing parents provide is recognised in policy as a vital service and resource to society (Department of Health, 2014a). Yet, as the parent carer role extends into the retirement years and parents begin to experience the normative declines associated with ageing, carer burden and concerns for their adult children's future support may be heightened.

There is a plethora of research on the challenges and the needs of children with ASD, as well as on their parents and siblings (Hall and Graff, 2010, Harris and Glasberg, 1994, Higgins et al., 2005). Yet, there is limited life course investigation and research into the needs and aspirations of families with an adult with ASD. The effects of lifelong support for adult children with ASD, changes in the carer role and adult sibling relationships remain under researched. Although parenting an adult with ASD changes over time, the challenges and stress are likely to persist across the life course (Barker et al., 2011). Parents of adults with ASD may have experienced years of compromises and adaptations. Moreover, older carers often experience smaller social networks with limited access to formal and informal support services (Chou et al., 2009, Gilbert et al., 2007). The next section will address lifelong parent caregiving for adult children with ASD, highlighting the positive and negative effects and concerns for future support.

### **Parents as carers**

Most carer research centres on older people as care recipients, not as lifelong care providers. Yet, many older parents of adults with ASD have maintained the carer role, providing the physical, instrumental and emotional care their children need, over their lifetime. Now these parents may have to address not only the support needs of their adult children with ASD, but their own age-related needs as well. The ageing carer and their adult children with ASD both need personal and personalised support for their continuity of wellbeing (Dillenburger and McKerr, 2014).



In a comparative analysis of older and younger family carers for an adult with intellectual disability researchers found older carers had lower educational levels, poorer health, and were more likely to be lone carers with decreased informal support networks (Chou et al., 2009). Compounding this profile are reports that older parents of adults with intellectual disability are frequently isolated from formal care services (Llewellyn et al., 2004, Llewellyn et al., 2010). Self-reliant behaviour and low service use has been explained by a generational and cohort effect: a reflection of when social resources and support services for families with a child with a developmental or intellectual disability were limited (ibid). Moreover, older adults' parents may lack knowledge and/or confidence in current service availability and support provision (Llewellyn et al., 2004).

#### **Affirmative aspects of life long caregiving**

Caregiving is not a unidirectional interaction, rather it is an interpersonal interaction that contains reciprocal aspects and impacts all family members (Lingler et al., 2008). Older lifelong carer mothers report positive benefits to the family of having an adult child with ASD living at home (Krauss et al., 2005). Mothers reported satisfaction in ensuring the wellbeing of their adult son or daughter with ASD and pleasure derived from their presence in the family. The companionship and gratification resultant from their relationship and interactions were also expressed. Older carers have developed expertise and competence in providing support for their adult children with ASD and often feel that caregiving has provided a sense of meaning and fulfilment in their life (Grant and Ramcharan, 2001, Haley and Perkins, 2004, Pruchno, 2003). They also feel that no one else is a capable substitute or as knowledgeable about the support needs of their adult children as they are (Gilbert et al., 2007). Heller and colleagues (2009) propose that family adaptation, acceptance and the stability of routines developed over time account for positive carer perspectives in later life. Barker et al. (2011) caution that although resilience and adaptation may occur, the cumulative effects of chronic stress and the challenges associated with parenting a child with ASD across the life course take an emotional toll on the mother's wellbeing. Thus, the cumulative effects of long term support can also have a negative effect on the parent's physical and mental health.

#### **The impact of carer burden**

In families with an adult with ASD the carer is typically the mother. Many older maternal carers are widows (Chou et al., 2009). These women may have experienced the added

burden of caring for their husband before his death and have lost the help and companionship that he may have provided. The demands of caregiving can be complex and intense with negative physical, psychological and behavioural effects on the lives and health of the carer. Compared with mothers of adults with other developmental disabilities (such as Down syndrome and cerebral palsy), mothers of adults with ASD experience elevated stress levels and compromised well-being (Abbeduto et al., 2004, Hayes and Watson, 2013). Diminished parental wellbeing is associated with autism symptoms, persistent behaviour problems and fewer social supports (Abbeduto et al., 2004). An older carer's health and reduced personal capacity to provide care, coupled with informal support attrition has been identified as a concern for the wellbeing of the carers and the care recipient (O'Connell et al. 2003). A carer whose physical and/or mental health is declining may not discern or have the capacity to address the changing health care needs of an adult with ASD. Increasing risks of isolation, carer burden and deteriorating health may place both the parent carer and the adult with ASD in a vulnerable situation.

Research has also demonstrated that parental resources and access to services can influence a carer's health and wellbeing (Hong et al., 2001). The limitations of supportive resources for adults with ASD compounded by the older carers' experience of smaller social support networks, as family and friends age and die, may amplify the level of carer burden. A strong association between parental emotional distress and/or burden and unmet needs has been identified among families supporting adults with ASD (Cadman et al., 2012, Hare et al., 2004). Highlighted among their concerns was the unmet need of planning for the future support of their adult children when they themselves were too old or infirm to care for them (Hare et al. 2004).

The parental carer role may change due to illness or death and an adult sibling may continue to provide the necessary support to ensure their brother or sister's wellbeing. The relationship and future care role of adult siblings of a brother or sister with ASD will be explored later in the chapter. In some families the lack or inability of a sibling to assume this role may necessitate alternative provisions and plans for the continuity of care for the adult with ASD. Older adults have difficulty and often avoid making future care plans in anticipation of their own dependency (Samsi and Manthorpe, 2011). For parents to make future care plans for

dependent adult children, the task is likely to be equally daunting. As such, research records very little concrete future family care planning for the transitional process out of parental care for a dependent adult ( Dillenburg and McKerr, 2014; Taggart et al., 2012).

#### **Parents and future support planning**

Much has been written on the subject of future support planning by ageing parents of adults with intellectual disabilities (Greenberg et al., 1993, Heller and Caldwell, 2006, Pruchno, 2003, Kelly and Kropf, 1995, Taggart et al., 2012, Dillenburg and McKerr, 2011) with a paucity of research investigating future support planning in families of adults with ASD (Hare et al. 2004). On the one hand, the needs of these two groups are similar in many respects, with both requiring effective long term support planning to ensure their safety and wellbeing. On the other hand, there are marked differences. For example, a comparative study between 70 aged matched adults with ASD and Down syndrome, found that adults with ASD had less independence and social contacts and more limited functional abilities and behavioural problems than their Down syndrome counterparts (Esbensen et al., 2010). In addition, compared with adults with intellectual disabilities, adults with ASD were less able to complete everyday tasks (Levy and Perry, 2011). Thus, the distinctive social and communication impairments, behavioural difficulties and sensitivities to change unique to people with ASD may present additional challenges in planning and preparing to meet their future support needs.

Given the challenges inherent to supporting an adult without ASD but with mental illness, researchers have emphasised that many of their older parents operate on a “one day at a time” philosophy: not making plans for when they can no longer provide support (Lefley and Hatfield, 1999). In addition, it has been found that parents’ plans for transferring care and responsibility for their adult children with intellectual disabilities is often at the informal level, lacking concrete discussions with those who are expected to provide the future support (Bigby, 1997, Taggart et al. 2012). Other researchers have found that the demands of caregiving over many years may have demoralised families to the extent that they simply are not able to plan for the future without professional urging and help (Rimmerman and Duvdevani, 1996). These and other factors such as fear, past experiences, anxiety, denial, interdependence and other impediments may influence a parent’s action-oriented planning for the future support of an adult child with ASD.

The overarching message from research on future support planning in families with an adult with learning and/or developmental disability is concern around limited preparation and concrete plans (Bigby, 1996, Taggart et al., 2012). Older carers of adults with severe learning disabilities and communication difficulties were particularly reluctant to make future support plans and worried that their adult children would not be able to make their needs known to someone else (Bowey and McGlaughlin, 2007). Compounding concerns that adults with learning disabilities may be unable to adequately communicate their needs, carers highlighted they may also have limited experience with self-advocacy and self-determination (Hubert and Hollins, 2000). Similarly, these may be matters of worry for older carers of adults with ASD. Without a future family support plan and an emergency intervention plan adults with ASD may experience a sudden and traumatic crisis intervention from social services when present support changes with potentially devastating and enduring consequences. Likewise the absence of a future support plan will limit the choices and control of the adult with ASD. Parents cannot assume siblings will be able to take on the responsibilities and demands of supporting a brother or sister with ASD when they are no longer able to. Alternative arrangements may be necessary with or without the existence of other family members.

### **Siblings of adults with ASD**

Most research involving families with an individual with ASD only considers the carer's perspective (often the mother), yet support may extend beyond the life and/or ability of the parents and involve other family members. Siblings are also likely to play a vital role in the lives of their adult brother or sister with ASD (Burke et al., 2012, Orsmond et al., 2009).

#### **The adult sibling relationship**

More than 80 percent of children in the UK have at least one sibling (Office for National Statistics, 2011). Siblings share genetic makeup, family and environmental experiences including common social and historical backgrounds growing up. Over the life course, the relationship between siblings may span more years than any other relationship. The sibling relationship is a durable relationship (including physical and emotional interactions) that may be nurtured or endured. Sibling relationships vary in quality, including closeness, communication and contact based on individual and family characteristics, responsibilities

and expectations (Lee et al., 1990). The sibling relationship also changes across the life course and extends into old age. With age, sibling relationships are typically discretionary in nature, with contact and interactions becoming a matter of choice. Siblings provide different types of support and interactions for each other as they age. Based on patterns of emotional and instrumental support, five types of sibling relationships have been described: intimate, congenial, loyal, apathetic and hostile (Cicirelli, 1991). Across the lifespan a committed loyal relationship, based on a strong sense of family obligation between siblings is the most commonly expressed sibling relationship (Rittenour et al., 2007). Loyal siblings provide emotional and instrumental support to one another (Rittenour et al., 2007). Certain factors have been identified that enhance the maintenance and reinforce sibling relationships in adulthood: gender, proximity and socioeconomic status (White, 2001). Women more than men tend to engage in kin keeping activities maintaining contact with their siblings (Waite and Harrison, 1992). Living closer, having a higher educational level and a large number of siblings seems to support adult sibling connections (White, 2001).

The amount and type of help adult siblings provide one another may be dependent on the sibling relationships developed in childhood and adolescence (Riggio, 2000). The life course perspective offers a framework for understanding how sibling roles and relationships change within the context of the family and the larger social-historical setting over time. Family interactions, experiences and expectations in early life are reinforced over time and form significant components of the attitudes, behaviours and decisions made in adulthood (Elder, 1998). In adulthood sibling relationships and obligations are often voluntarily maintained. Adult siblings can usually be relied on for help during times of crisis, and typically cooperate with each other in order to care for their elderly parents (Cicirelli, 1989). With the death of parents and their own shrinking social networks, sibling relationships may take on renewed importance in old age (White, 2001). The responsibility and commitment to a sibling's welfare reflects an established norm of family behaviour. However, the hierarchy of help within most families is exchanged in a vertical direction from spouse and children, with siblings providing a secondary, supplementary position (White, 2001). The life course perspective considers the experiences of a series of normative transitions (leaving home, getting married, having children and retiring) across an individual's life span. As individuals make these transitions the sibling relationship becomes less prominent. Yet, when these

transitions are not accomplished (marriage and having children) or are greatly delayed (leaving home) the supportive sibling relationship may remain of central importance. For a sibling of an adult with ASD this may well be the case.

#### **Adult siblings of a brother or sister with ASD**

Sibling relationships are developed within the context of the family. The interactions and relationships within a family are bidirectional with the behaviours, actions and reactions of one person affecting the others (O'Connor et al., 1997). A brother or sister with ASD may affect the quality of the sibling relationship, as well as the family experiences and expectations (Karst and van Hecke, 2012, Rivers and Stoneman, 2003). Family functioning may be negatively impacted, and social interactions and relationships strained (Rao and Beidel, 2009). Research suggests a higher divorce rate among families with children with ASD (Hartley et al., 2010, Freedman et al., 2012, Saini et al., 2015). As discussed in Chapter 2, ASD is a heritable condition, with the risk rate for siblings of children with ASD being greater than among the general population (Ozonoff et al., 2011, Piven et al., 1997). A significantly greater number of siblings of a brother or sister with ASD display the broad autism phenotype (BAP), sharing milder versions of some of the defining traits of autism (Freitag, 2007, Parr and Le Couteur, 2013, Yirmiya and Ozonoff, 2007).

Individuals with ASD have a range of social, behavioural and communication limitations that may impact their abilities to socialise and form relationships. Siblings growing up with a brother or sister with ASD will likely experience disruptive behaviours and social limitations associated with their sibling's disorder (Kaminsky and Dewey, 2001). They may have to assume a more mature relationship role helping, teaching and providing care for their brother or sister with ASD (Stoneman, 2005). In adulthood there is an increased probability that siblings will assume some responsibility of care for their brother or sister with ASD when parents can no longer maintain the caregiving role (Burke et al., 2012, Orsmond et al., 2009).

All sibling relationships vary in warmth/closeness, companionship, affection, nurturance, conflict/rivalry and admiration. In the context of a developmental disorder the quality of the sibling relationship is influenced and fostered by the parents (Schuntermann, 2007). Raising a child with ASD places high demands on the parent's time, attention, and resources, possibly leaving little reserve for other family members (Rao and Beidel, 2009). A child with ASD can

tax the social and emotional experiences of family members with disruptive, inappropriate, impulsive and aggressive behaviours, severe communication deficits, and rigid and restricted rituals and routines. Moreover, their behaviour may elicit critical and judgemental responses from others. Typically developing siblings of children with ASD have reported that they are sometimes disturbed by their sibling's behaviour (Rivers and Stoneman, 2003). Past research has shown that siblings of young children with ASD spend less time together and their relationships is not as close compared with siblings of children with Down Syndrome (Bågenholm and Gillberg, 1991, Kaminsky and Dewey, 2001, Knott et al., 1995). In addition, parents direct more attention and time to children with disabilities than to typically developing siblings (Stoneman, 2005). Lainhart (1999) noted that many adolescents and young adult siblings of a brother or sister with ASD expressed anger about how their sibling with ASD affected the family's life. The sibling's perceptions of reduced parental attention and time may persist into adulthood (Schuntermann, 2007).

Research examining the psychosocial outcomes of siblings of children with ASD shows mixed findings. On the one hand, studies have identified negative outcomes including increased social and behavioural problems (Meyer et al., 2011, Rossiter and Sharpe, 2001) and greater adjustment and peer problems with lower levels of prosocial behaviours (Orsmond and Seltzer, 2007b). On the other hand, research has also found siblings of children with ASD to be well adjusted with positive self-esteem (Kaminsky and Dewey, 2002, Orsmond and Seltzer, 2007b, Pilowsky et al., 2004). In a longitudinal study of a sample of 117 siblings with a brother or sister with ASD Seltzer and colleagues (2003) found the presence of hyperactivity disorder, ASD and psychiatric disorders. Additionally, depression and loneliness were found to be more prevalent in siblings of children with ASD (Pilowsky et al., 2004). Similarly, the severity of the sibling with ASD's disabilities and behavioural problems may have a greater impact on the psychological wellbeing and behavioural problems of the typically developing siblings (Hastings, 2003).

Conversely, the positive impact of sibling relationships on social and emotional development may be underemphasised. Kaminsky and Dewey (2001) in a comparative study of siblings with brothers or sisters with a developmental disability found that siblings exerted a positive influence on the social behaviours of their disabled brothers and sisters. Expanding on this

positive effect, children with ASD have been found to make more vocal and verbal initiations towards their siblings than towards their parents (El-Ghoroury and Romanczyk, 1999).

Siblings act as mentors, role models, teachers and socializing agents for each other. As a result of the increased demands involved in caregiving for a child with ASD, siblings are more likely to be recruited into caring and supportive roles in childhood and adolescence. Research has demonstrated that when these demands become burdensome sibling relationships may suffer with greater levels of conflict, less positive interactions and more behaviour problems (Schuntermann, 2007). When one child has an intellectual or developmental disability the sibling relationship is often described as being asymmetrical (Stoneman, 2005). For instance, the typically developing sibling frequently assumes a dominant role helping, teaching and managing their brother or sister with disabilities. The degree of the role asymmetry increases with the limitations of the sibling with disabilities. While most sibling relationships become more egalitarian and reciprocal with age, a relationship with an adult sibling with ASD may remain asymmetrical depending on the level of disabilities (Stoneman, 2005). Adult siblings with a brother or sister with ASD may be expected to assume caregiving responsibilities for their brother or sister after their parents die (Orsmond and Seltzer, 2007a). In adulthood siblings often assume the roles of advocates, mediators, supervisors and/or caregivers for their siblings with intellectual or developmental disabilities (Bigby, 1997).

However, a close relationship developed in childhood between siblings of a brother or sister with ASD may deteriorate in adulthood (Karst and van Hecke, 2012). In a large-scale American survey, Hodapp and Urbano (2007) found that in particular when the sibling with ASD was 45 years of age and older there was less contact and a decreased closeness to the sibling. Corroborating these findings Orsmond and Seltzer (2007) reported lower levels of contact and less positive affect in siblings of adults with ASD when compared with siblings of adults with other developmental disabilities. This more distant relationship may have significant impacts on the adult sibling's ability and willingness to assume future support responsibilities.

Having a brother or sister with autism is likely to confer added challenges and stress for siblings. The sibling relationship may be influenced by limitations in communication and



social skills, challenging behaviours, and restricted social activities. The family environment may have the additional strains of family members with BAP. Perhaps it is not possible to disentangle how genetic and environmental risk factors in a family of a child with ASD combine to cause and affect various outcomes in typically developing siblings. The severity of the disability and behaviour problems, the extent of BAP characteristics in the parents and siblings, family stress levels and the marital composition of the family may all exert influencing factors. Likewise the bearing of these factors may determine the ability and motivation of the adult sibling to assume future care responsibilities for their brother or sister with ASD.

#### **Siblings and future support planning**

The influences and roles that siblings maintain in the family change over time. Family expectations of supportive roles and behaviours of siblings of an adult with ASD may not be explicitly detailed and yet may be implicitly assumed. After the death or incapacity of parents, a sibling of a brother or sister is likely the closest relative. For an adult with ASD who requires support and supervision this role may be expected to be assumed by a sibling (Orsmond and Seltzer, 2007a). Studies have shown that one sibling is typically identified in families for the future support role (Bigby, 1997, Greenberg et al., 1999). Additionally, siblings anticipated assuming more future responsibility for a brother or sister with an intellectual or developmental disorder if they were the lone sibling without a disability (Burke et al., 2012). The extent of contact and interactions between the siblings is also associated with future expectations in this role (Krauss et al., 1996, Burke et al., 2012). For example, siblings who live in close proximity and have frequent interactions with their brother or sister with disabilities highly anticipate a future support role.

The adult siblings of a brother or sister with ASD may be the first generation to assume support responsibilities post their parents' care. Moreover, family roles and relationships change across the life course. Consideration of these changes and the needs, desires and ability of the sibling to assume a support role should be considered by family members and service providers. In some families the lack or inability of a sibling to assume this role means that alternative plans and provisions for the continuity of support for the adult with ASD need to be made. In addition, research to date on the relationship and future support expectations of adult siblings with a brother or sister with a learning or developmental disability has typically used survey methods, and is limited solely to the sibling's perspective (Orsmond and Seltzer,

2007a). The perspective of the adult with ASD is missing and should be considered where possible when discussing and planning future support.

The involvement of siblings in the planning for the future care of a brother or sister with ASD has received little attention. The magnitude of the responsibility they may assume merits their input in the family's planning. Although some research has investigated siblings' expectations for assuming future care responsibilities for a brother or sister with developmental disabilities, research exploring their inclusion in the decision making process is severely limited. Heller and Kramer (2009) conducted an online survey of 139 adult siblings of an adult with developmental disabilities concerning their involvement in family future planning and found that very few families had included the nondisabled sibling in the planning process. Little research has explored future support planning with an adult with ASD, identifying their future aspirations and supportive needs, from their perspective (Dillenburger and McKerr, 2014). The current research will begin to fill that gap using qualitative face to face interviews with adults with ASD and their adult siblings on the topic of future care planning, including aspirations and expectations.

### **Partners of adults with ASD**

Current knowledge on the development of intimate relationships and marriage among adults with ASD is limited (Renty and Roeyers, 2007). The literature suggests few adults with ASD develop long term relationships or marry (Howlin and Moss, 2012, Renty and Roeyers, 2006, Sperry and Mesibov, 2005). A systematic review of follow-up studies on adults with ASD, reported an average of 14% of participants rated as being married or having long-term relationships. Individuals with ASD have difficulty in peer interactions, lack appreciation of social cues, are egocentric, and frequently display socially and emotionally inappropriate behaviours (Cederlund et al., 2010). However, while adults with ASD may lack social competence and have limited emotional understanding, which may compromise the development of intimate relationships, such as dating or marriage, Stokes and colleagues (2007) reported many desire social and romantic relationships, and actively seek out such relationships. Moreover, when friendships and intimate relationships do succeed, the friends and partners are generally very candid and literal, do not presume knowledge on the part of the person with ASD, explain subtle social nuances, and demonstrate compassion (Sinclair,

1992, Stanford, 2003). These informal supports can be an invaluable resource for individuals with ASD. While a growing source of information from a personal perspective about long-term relationships for adults with ASD is available, little empirical research has been conducted in this area (Renty and Roeyers, 2007). This research explores the relationships and support, reported by a small number of adults with ASD and their partners.

### **Impact of changing demographics for family long-term care**

Great changes in the diversity of the family unit (e.g. divorce, step parents and siblings, single parents) may also have long term implications for care and support of adults with ASD. In a decade review of research on ageing and family life, Silverstein and Giarrusso (2010, p. 1039) emphasized that “relationships (...) have become more fluid and less predictable, as reduced fertility and increased rates of divorce, remarriage, and stepfamily formation have altered the micro context in which intergenerational, spousal, and sibling relationships function.” This statement underscores not only the changes in the family structure and relationships across time, but also brings to light the possible impact of changing family demographics for family future support for adults with ASD. Demographic changes in the family have, and will continue to, effect individuals with ASD and their family members. Decreased family size means fewer siblings, which may impact the value of their relationship and the roles particularly with regards to future support responsibilities they may assume. Adults with ASD may lack family support systems to provide the continuation of support. In single child families where the only child has ASD this presents an even more difficult situation, as both the elderly parents and the adult with ASD may have support needs.

Increased life expectancy and significant reductions in fertility over the last few decades had and will continue to have implications for family and societal care roles and responsibilities (Cohen, 2003). Families differ in their ability to provide care and support. Families with fewer children to assume future support responsibilities for an adult brother or sister with ASD may be more dependent on social services to fill these needs. Increased rates of divorce, remarriage and step and half-sibling relationships may further diminish the availability of a family member to fulfil long-term support roles and responsibilities for an adult with ASD. These changing demographics highlight how relationships, roles and responsibilities are

interdependent on the family, societal and policy environments consistent with the life course perspective (Silverstein and Giarrusso, 2010).

### **Family support and future planning for adults with ASD**

Hatzidimitriadou and Milne (2005) recommends that strategic future support planning for an adult with developmental disabilities should begin early to enable carers to both receive support to maintain care and to provide support to the future carer and adult child to ensure a secure transition. Researchers emphasised that transition of care should be a gradual process and not a sudden event occurring at a time of crisis (Bigby, 1996). A gradual transition process enables adjustments and acceptance to be achieved by all family members (Taggart et al., 2012). This may be particularly relevant for adults with ASD who have limitations in adaptability and sensitivities to change. Lifelong carers may find relinquishing care and passing on the responsibilities for an adult child with ASD equally as difficult and need adequate time to make this transition successfully. Small changes over time may be better tolerated with choices and preferences accommodated for all participants.

### **Chapter summary**

This chapter framed family support roles over time in families of an adult with ASD. Patterns of support and expectations for receiving and providing support across the life course are part of a continuing process of relationships and interaction of linked lives among parents, children, other kin, and unrelated individuals. The impact of providing lifelong care to family members with ASD needs greater research and attention. Likewise local authorities and policies must direct special attention and priority to these carers and their adult children with ASD. With limited knowledge of the service and support needs of adults with ASD, service providers and family members may be ill prepared to meet their future support needs post-parental care. Moreover, the preferences, and concerns for future support of adults with ASD from the perspectives of all family members must be included and considered. The next chapter describes the methodology of this study, beginning with a brief reminder of its aims and objectives.

## Chapter 5: Methods

This chapter outlines the methods used in this study. First, it reviews the aim and objectives of the study. This is followed by a discussion of the research design. Then the research questions, study sample, inclusion and exclusion criteria and age group banding are explained. Next it provides a detailed discussion for each stage of the study including: the research questions, sample, recruitment, study site, the research instruments, procedure, and data analysis. Finally, ethical issues associated with the study are addressed.

### Aim

The key aim of this study is to explore the support needs, family roles and relationships and long term support planning in families with an adult with ASD from a holistic family perspective. Although ASD is a developmental disorder which is known to persist into adulthood, little is known about the support needs and family relationships in this group. Many adults with ASD continue to be supported by their parents, but family dynamics, and by whom, and how, support will be provided post-parental care remains an unexplored area. In particular, this study sought to investigate the support needs of adults with ASD both from their perspective, and that of other family members, and to examine family future plans to meet their needs post-parental care.

This study built on an earlier research project, ‘Service use and needs among people with ASD during the transitional years from adolescence to young adulthood’, that formed part of a wider 5 year programme funded by the National Institute for Health Research (NIHR) (RP-PG-0606-1045) entitled, “Crossing the divide: Effective treatments for people with neurodevelopmental disorders across the lifespan and intellectual ability” (Murphy, 2007 to 2013). Within this programme was a three-year longitudinal study to investigate service use and needs among people with Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) at the transition from adolescence to young adulthood (from 14 to 24 years). This is referred to here as the NIHR Transitions Study. In that study face-to-face interviewer administered questionnaires were used to assess needs, demographic and health factors associated with measures of service at two time points over a three year period. The

NIHR Transitions Study contained 101 families caring for a young person aged 14–24 years with a childhood diagnosis of ASD. Findings showed that despite continuing needs and a high prevalence of psychiatric co-morbidities, many adolescents and young adults with ASD were not receiving help from services (Cadman et al. 2012). The current study replicated the methods and some instruments used in the ‘Service use and needs among people with ASD during the transitional years from adolescence to young adulthood study’, with an older age group of adults with ASD (18 years of age and older) and added qualitative interviews with adults with ASD and their family members. Additionally, some data from the NIHR Transition Study are used in the current study.

### **Research design**

This study used a cross-sectional mixed methods observational research design using face-to-face quantitative questionnaires and interviews with adults with ASD and their family members. The diverse issues of need and support are interlinked and understanding their complexity required a research methods design that facilitated exploration at more than one level. Therefore, an exploratory sequential design was adopted to research the support needs and family dynamics of adults with ASD. The two-stage structure consisted of the collection of quantitative questionnaires with adults with ASD at Stage One, followed by semi-structured qualitative interviews with adults with ASD and their family members at Stage Two.

Although debates about the compatibility of different theoretical approaches to research continue, there is wider acceptance of the value of combining methodologies across a range of disciplines (Creswell et al., 2011, Morgan, 2013, Tashakkori and Teddlie, 2010). When the specific strengths of quantitative and qualitative approaches are combined they can be complementary and help to avoid the biases inherent in each approach (Johnson et al., 2007). Moreover, using quantitative and qualitative approaches can provide different perspectives of the same phenomena and as such offer more and richer evidence (Creswell et al., 2011). The presumed advantage of using mixed methods is that both quantitative and qualitative research, in combination, provide a better understanding of a research problem or issue, than either research approach alone (Clark and Creswell, 2011). While the current support needs of adults with ASD could be identified and enumerated with quantitative methods, information about their lived experiences from multiple perspectives demanded a qualitative

approach. As such, each method yielded complementary insight into both need and support for adults with ASD.

### **Inclusion criteria**

Four inclusion criteria were used to assess and select participants in this study. First, participants had to be 18 years of age or older. Second, they had to have received an ASD diagnosis from a health professional with an administered Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1997, Rutter et al., 2003) or Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000, Gotham et al., 2007). The assessment of all ADI-R, and ADOS were conducted and recorded by a professional or qualified researcher in advance of this study. All reported ADI-R, ADOS and intelligence quotient (IQ) scores in this study were obtained from the patient records in the BCG database and data collected from the NIHR Transitions Study. Potential participants were selected if they had a diagnosis of High Functioning Autism (HFA), Asperger Syndrome (AS) or childhood autism. Asperger Syndrome and High Functioning Autism (HFA) are defined here as an individual who meets the criteria for autism in the absence of a global learning disability (ICD-10, 2017). High-functioning autism (HFA) is a term applied to people with autism who are deemed to be cognitively "higher functioning" (with an IQ of 70 or greater) than other people with autism (ibid). Individuals with HFA and AS have average or above average intelligence but may struggle with issues related to social interaction and communication (Gantman et al. 2012; Mazzone, Ruta and Reale, 2012). An IQ is a total score derived from one of several standardised tests designed to assess human intelligence (Macintosh, N.J. 2011). On most IQ tests, a score of 100 is considered standard or average intelligence, and a score of 70 or below suggests intellectual disability (Crane et al. 2009). However, intelligence is a complicated construct when it comes to autism. Social, communication and behaviour difficulties may give the appearance of intellectual disability and make it challenging to test IQ. Additionally, an IQ test measures only a part of what we consider as intelligence, which includes a person's ability to solve problems, reason, plan, think abstractly, and learn from, and adapt to, the world around them. However, researchers have found that adaptive skills of individuals with autism may lag behind their IQ level (Charman et al. 2011). For example, an adult with autism's daily living skills may be significantly below expectations for someone of their age

and IQ. Additionally, because childhood autism may include a wide range of IQ levels only potential participants without a learning disability were selected for recruitment.

Third, participants had to have mental capacity to consent to participate in this study. The first principle of the Mental Capacity Act, (2005), states that capacity to consent is assumed unless it is proven otherwise. However, some neurological, psychological and/or behavioural markers may suggest lack of capacity for some decisions at some times. Capacity is fluid in time and with respect to subject. Given the nature of this study, it was possible that some people who may be eligible to participate may lack capacity. Indicators of potential lack of capacity include (but are not restricted to) the diagnosis of learning disability, an IQ score of less than 70, and significant deficits in adaptive functioning or other signs or symptoms of mental disorder that might compromise capacity to give informed consent (Mental Capacity Act, 2005). Thus where it was considered appropriate by the researcher for capacity to be assessed, a capacity assessment tool was used to address the following questions:

1. Does the person have an impairment or disturbance in the functioning of the mind or brain?
2. If so, can they:
  - ♦ understand the information relevant to the decision?
  - ♦ retain that information?
  - ♦ use or weigh that information as part of the process of making the decision?
  - ♦ and can the person communicate his/her decision (whether by talking, using sign language or any other means)?

This was based upon the principles outlined in section 3(1) of the Mental Capacity Act, 2005. The researcher received training from Dr. Dene Robertson (consultant psychiatrist at the Mental Impairment and Evaluation Service, Bethlem Hospital) in assessing mental capacity to consent. If the adult was deemed unable to consent by the interviewer, the interview was not to proceed. This did not happen in any case in this study. The fourth inclusion criterion was participants had to understand and speak English, as there were no funds or resources for translation and interpretation services.



### **Exclusion criteria**

Potential participants were excluded for three reasons. First, although adults with a diagnosis of partial-ASD, pervasive developmental disorder (PDD) or PPD-unspecified and atypical autism are also part of the autistic spectrum, they were not included in this research. These diagnostic labels were used as exclusion criteria because they are applied to individuals who are on the autism spectrum but who do not fully meet the criteria for an autism diagnosis (American Psychiatric Association, 2000). They may be considered subthreshold autism; someone who has some, but not all characteristics of autistic disorder or Asperger's Syndrome (ibid). Moreover, the diagnosis of atypical autism is commonly attributed to individuals with profound cognitive impairment and low functioning abilities which constrain assessment of specific diagnostic behaviours of autism (WHO, 1992). Controversy exists regarding the differences in overlapping diagnostic criteria and the differences in the disorders comprising the autism spectrum (Matson, Nebel-Schwalm, and Matson, 2007). Due to the ambiguity surrounding the boundaries of these disorders they were excluded from this study. Second, in an effort to meet the criteria of mental capacity the presence of a learning disability was an exclusion criteria for recruitment. The presence of a learning disability was noted on the BGC database and none of these individuals were selected for recruitment. Thirteen percent of the NIHR Transitions Study sample had a learning disability as informed by the parent and no data were used, or recruitment sought, of these individuals. Third, geographic location, those residing outside the boundaries of a day trip from London, resulted in exclusion due to prohibitive costs and no funding for the study for overnight stays.

### **Age group banding**

In the current study, age group classifications were used as a meaningful representation of information comparability to explore possible sociohistorical influences on the support needs of adults with ASD. Two age groups of adults with ASD were defined: 18-29 years of age and 30 years of age and older. There is little consensus on age group definitions in adulthood. Arnett (2007) has proposed the concept of emerging adulthood to be the years between 18 and 25, while others have broadened the range to include 29 years of age (Lenhart et al., 2010, Munsey, 2006). Age group classifications in research of adults with ASD is missing, with participants older than 18 years of age designated simply as 'adult'. Moreover, most research samples of adults with ASD are typically skewed to mainly 20 year olds (Wright et

al. 2017). Clearer specificity and consistency of age group classifications in research may highlight heterogeneous needs and distinct life course transitions that span adulthood and ageing with ASD.

The rationale for age group delineation at the age of 30 years in this study was made on a number of factors. First, it was thought that adults with ASD 30 years of age and older may have experienced different socio-historical environments growing up that may have influenced their life course in comparison with younger adults with ASD 18-29 years of age (see Chapter 3). These differences may be reflected in the adult with ASD's service use and needs, and family plans and concerns for the future. Second, setting the older age group as 30 and older was also appropriate, as according to the Office for National Statistics (2016) it is at this age and older that people are most likely to be co-habiting or married, and therefore likely to be establishing independent lives. Third, it was reasoned that the advancing age of parents of adults with ASD 30 years and older may have prompted more established future support plans for continued support of their adult children with ASD than those of younger aged adults. Although, the age category 30 years of age and older remains broad, limited recruitment among older aged adults with ASD necessitated this age group banding. The adult with ASD age group categories of 18-29 years of age, and 30 years of age and older were maintained throughout this study.

## **Stage One: quantitative data collection**

### **Research questions**

The specific research questions addressed by quantitative instruments in this stage of the study were:

- (i) What are the needs of adults with ASD?
- (ii) How and by whom are their needs being met?
- (iii) What are the unmet needs of adults with ASD?
- (iv) What is the health service use of adults with ASD?

### **Sample**

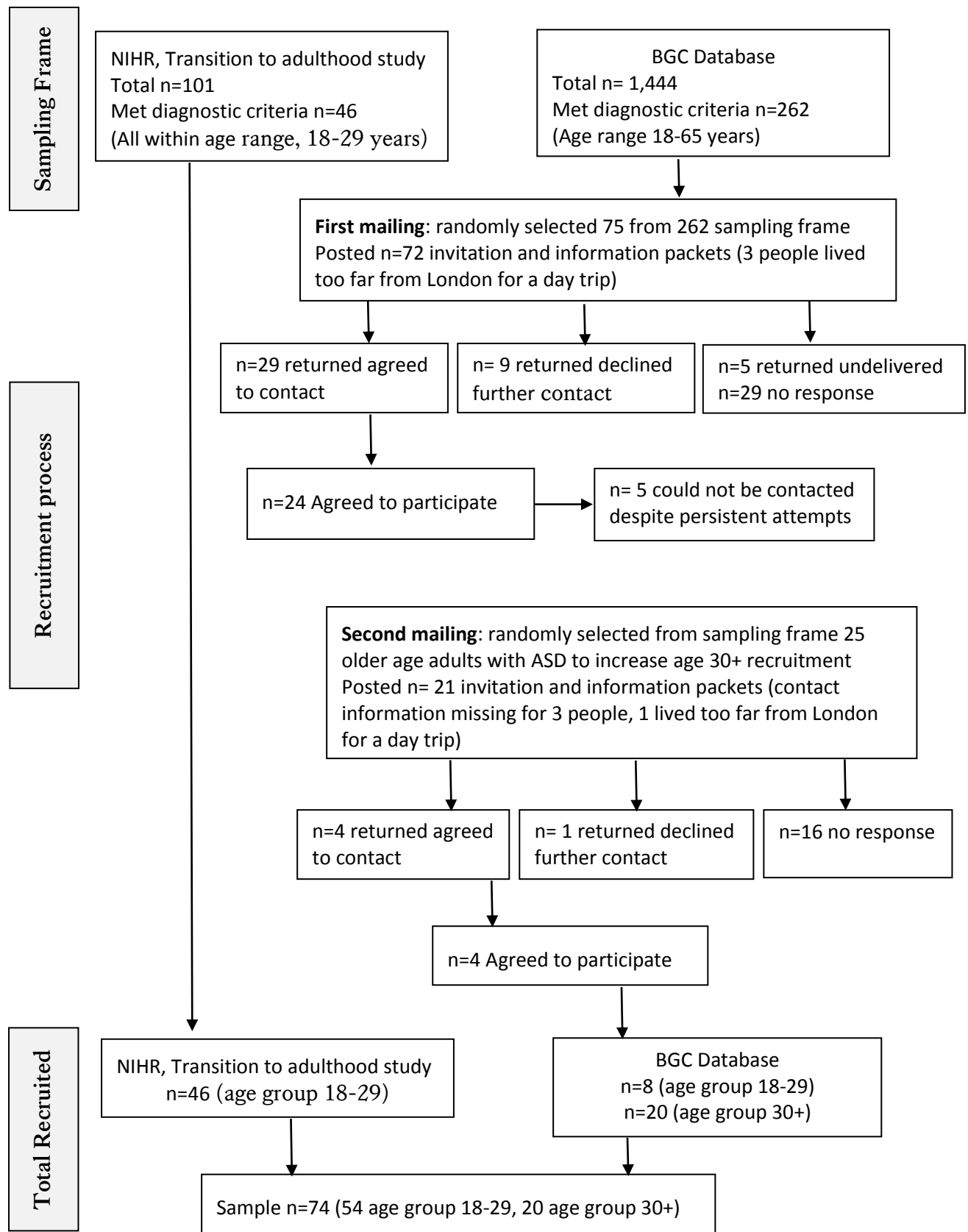
The sampling strategy was purposive (Smith, 2015) since it allowed access to particular groups who were able to provide a specific insight into an identified phenomenon. A

purposive sampling method is effective when only certain people can serve as primary data sources due to the nature of the research design, aims and objectives (Ritchie et al., 2013). In purposive sampling personal judgment needs to be used to choose cases that help answer research questions or achieve research objectives (Tongco, 2007). Potential participants were selected using particular inclusion and exclusion criteria, as detailed above. The sample for the quantitative stage included 74 adults with ASD.

#### **Sample recruitment and response**

Participant recruitment of adults with ASD for Stage One were identified from two sources: the NIHR Transitions Study, '*Service use and needs among people with ASD during the transitional years from adolescence to young adulthood*' study, and those listed as willing to be contacted for research, who met participation criteria, from the patient caseload of the Behavioural Genetics Clinic (BGC), Maudsley Hospital, London. Quantitative data from the CANDID and adapted CSRI questionnaires previously collected at Wave 2 of the NIHR Transitions Study for 46 individuals who met criteria for this study were included in this sample. This was the last point of data collection in the NIHR Transitions Study and closer in time to follow-up qualitative interviews in this study. CANDID and adapted CSRI information for 28 other adults with ASD recruited through the BGC database was collected by the researcher in face-to-face meetings. Recruitment for Stage One began in February 2014 and continued until a total of 74 eligible adults with ASD had been recruited in August 2014 (see Figure 5.1).

Figure 5.2 Recruitment procedure flow chart: Stage One



It can be seen from Figure 5.1, recruitment from the BGC database proceeded as follows. First, access to the anonymised database of 1,444 entries was assessed for inclusion and exclusion criteria for this study, as outlined in the section above. This resulted in a sampling frame of 262 potential participants. De-anonymised contact information for 75 adults with autism randomly chosen, who met age and diagnostic criteria from the BGC database was requested. Seventy-five was believed to be a manageable amount for a first mailing being conscientious of the cost as the study had no funding. Three of these people lived at a distance greater than a day trip to and from London and were not selected for recruitment. A research study packet including: a letter of invitation, an information sheet explaining the study, together with a contact form and a stamped addressed envelope for return to state their interest in participation, was sent by post to 72 adults with ASD from the BGC database (see study packet documents in Appendix B). Twenty-nine adults returned the study contact form agreeing to have the researcher contact them by phone to discuss the study and participation. Of those who agreed to contact, 5 people could not be reached after multiple calls and messages. The other 24 adults with ASD participated in the study. Nine people returned the study contact form declining participation and 5 study packets were returned as undelivered. No reasons were provided on the form for those who declined participation. No response, either by mail or telephone, was received for 29 out of the 72 study packets mailed to possible participants, resulting in a response rate of 40%.

In an effort to increase the number of older age group participants de-anonymised contact information for 25 adults with autism 30 years of age and older randomly selected from the sampling frame at the BGC was requested. Contact information was missing for three people and one lived too far away for recruitment. A second mailing of 21 packets were sent to adults with ASD from this list. Four people from this mailing agreed to participate and one declined. No response was received from 16 people. The response rate for the second mailing was 24%. In the interest of time and cost no further recruitment was conducted.

A telephone conversation to further explain the study, the anticipated length of time of the meeting and to establish a place and time to conduct the questionnaires followed receipt of interest to participate. Consent to participate was obtained verbally over the phone when

arrangements were made to meet and a written consent on the day of the meeting prior to beginning the questionnaires. Forty-six participants from the NIHR transitions study met inclusion criteria for this research and their quantitative data (demographic information, adapted CSRI and CANDID questionnaires) was included in the younger age group findings without the participant being required to complete these instruments again. Additionally, the researcher collected data from eight other young adults with ASD recruited from the BGC database bringing the total number of younger age group participants in Stage One to 54 people. Twenty adults with ASD aged 30 years and older recruited from the BGC patient caseload database completed the questionnaires with the researcher and their information was included in the older age group.

#### **Study site**

Face-to-face meetings to collect quantitative data were conducted at the person's home or at the Institute of Psychiatry (IoP) King's College London, unless a different location was preferred by the participant. Most participants found their homes to be the most convenient location for them, though four participants preferred to be interviewed at other locations. They chose a coffee shop or café near their home that offered enough privacy to ensure confidentiality of the administered research instruments.

#### **Quantitative research instruments**

The instruments used in Stage One of this study, the CANDID and an adapted CSRI were administered in the format of a face-to-face meeting for both this study and the NIHR Crossing the Divide study (see Appendix C).

#### *The Client Service Receipt Inventory (CSRI)*

The CSRI is a semi-structured questionnaire of health and social care service use. It was developed in England by members of the Centre for the Economics of Mental and Physical Health in the mid-1980s and has been widely employed in numerous mental and physical health care evaluations (Beecham and Knapp, 2001). It has been used in several studies on the service consumption of adults with intellectual disability or ASD (Felce et al., 2008, Hallam et al., 2006, Järbrink and Knapp, 2001, Knapp, 2005). The CSRI consists of a series of questions about a range of services used in a defined space of time (e.g. the last three months

in the present study). The retrospective period (prior to the date of the interview) chosen was a compromise between accuracy that comes from not asking respondents to think back too far and the comprehensiveness which can only come by allowing sufficient time to elapse for the possible use of various services.

A modified version of the CSRI (Beecham and Knapp, 2001) tailored to adults with ASD was used to assess service use of the adults with ASD. Adapted for this clinical group the CSRI asked information about the adult's frequency and type of service use in the last three months prior to the meeting, for autism and for reasons other than for autism, with those answering yes recorded as currently being in touch with services (coded as 1). The first section of the adapted CSRI covers background and client information, including personal, educational, and demographic questions relating to the participant. Additionally, it enquires about the person's household, the number of occupants in the household, and their respective ages. An employment section asked about the person's employment status and hours worked per week. The service receipt section of the adapted CSRI questionnaire provided a list of various different service types. For example, hospital services including GP, and practice nurse; community services such as psychiatrist, social worker and occupational therapist; and other community services including solicitor, key worker and alternative therapist and websites or helplines. For each service type, the number of contacts over the chosen retrospective period and the average duration of these contacts are requested. Using the modified CSRI as part of a face-to-face interview allowed for probing and clarification of responses.

#### *The Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities (CANDID)*

The level of need of the adult with ASD was captured using the Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID) (Xenitidis, 2003). The CANDID is a questionnaire specifically designed for adults with developmental and intellectual disabilities who also have mental health problems. It was originally developed to assess the needs of people with severe mental illness in the form of the Camberwell Assessment of Need (CAN) (Phelan et al., 1995) in relation to the requirements of the National Health Service and Community Care Act (House of Commons, 1990). Since then a number of variants have been developed, based on the same principles, to assess the needs

of various subgroups of people with mental health problems; including: adults in contact with forensic services, the Camberwell Assessment of Need-forensic version (CANFOR) (Thomas et al., 2003); older people, the Camberwell Assessment of Need for the Elderly (CANE) (Orrell and Hancock, 2004); and adults with developmental and intellectual disabilities, the CANDID, described here. The CANDID has been rigorously developed and tested by a multidisciplinary team at the Institute of Psychiatry of King's College London and is used around the world to help health and social care professionals understand the difficulties experienced by people with learning and developmental disabilities (Martin et al., 2005, McCausland et al., 2010). It has been found valid and reliable in both community and hospital settings (Xenitidis et al., 2000).

The CANDID has been used previously to explore the needs of young adults with ASD as they transitioned to adult services, but findings reported were based on the parent's response and not that of the young adult themselves (Cadman et al., 2012). All CANDID needs reported in this study are exclusively those articulated by participating adults with ASD. The importance of obtaining the perceptions of service users with regards to needs, priorities and planning has been emphasised, especially as they may differ substantially from those of assessors (Hancock et al., 2003, Walters et al., 2000).

There is no 'gold standard' measure to assess the needs of adults with ASD. However, given that ASD is a developmental disability and is often associated with intellectual disabilities and comorbidities of mental health problems, it was judged that the CANDID would be the most appropriate of all the needs assessment instruments available. A key advantage of the CANDID is that it takes into account not only the service user's needs, but three other considerations: help provided by relatives and services; perceived need for help from services; and adequacy of, and satisfaction with, help provided in each area assessed. It is suitable for use with adults with all levels of learning disabilities as it can be completed by an informant, and is administered by an interviewer. It is a comprehensive instrument that covers a wide range of social, physical health and mental health care needs.

The assessment using the CANDID involved the interviewer asking the adult with ASD questions about each of the 25 domains of need, with the interviewer recording their response



(see Table 5.1). For each domain the adult with ASD was asked whether there was a significant need ('yes' was coded as 1 and 'no' as 0). If yes, further questions were asked to ascertain if sufficient formal and/or informal support was being received. If adequate support was received the need was classified as 'met' (regardless of whether it was met by formal or informal support); if insufficient support was received the need was classified as 'unmet'. Both met and unmet need scores were calculated by summing the number of domains where a need was recorded. A total needs score (range = 0-25) was calculated by summing the met and unmet need scores (Xenitidis et al. 2000).

Table 5.1 CANDID domains and topic questions

Domain	Topic Question
Accommodation	Do you lack a current appropriate place to live?
Food	Do you have difficulty in getting enough food?
Looking after the home	Do you have difficulty looking after the home?
Self-care	Do you have problems keeping yourself clean and tidy? Do you ever need reminding or help?
Daytime activities	Do you have difficulty with regular, appropriate daytime activities?
General physical health	Do you have any problems with your physical health?
Eyesight/hearing	Do you have any problems with seeing or hearing?
Mobility	Do you have restricted mobility?
Seizures	Do you have any kind of seizures?
Major mental health problems	Do you have any symptoms of severe mental illness?
Other mental health problems	Do you suffer from current psychological distress, anxiety or depression?
Information	Have you had clear verbal or written information about your condition and treatment?
Exploitation risk	Is anyone trying to take advantage of you in any way?
Safety of self	Do you ever have thoughts of harming yourself? Do you ever actually harm yourself? Do you put yourself in danger in any other way?
Safety of others	Do you think you could be a danger to other people?
Inappropriate behaviour	Do other people get annoyed, upset or angry because of your behaviour?
Substance misuse (alcohol & drugs)	Do you have an alcohol or drug problem?
Communication	Can you understand what other people say to you? Can they understand you?
Social relationships	Do you have enough friends? Do you wish you had more contact with other people?
Sexual expression	Do you have any sexual difficulties?
Caring for someone else	Do you have difficulty looking after another person?
Basic education	Do you have difficulty with reading, writing? Can you count your change in a shop?
Transport	Do you have any problems using public transport?
Money budgeting	Do you have problems budgeting your money?
Welfare benefits	Are you sure that you are getting all the benefits you are entitled to?

## Procedure

First following standard practice, the participants were reminded of the study brief, any questions were answered and written consent was obtained. The questionnaires were administered as a structured interview. Each question was read out in full to the participants, with the researcher recording the responses provided by participants on the paper-based questionnaire. The aim of this approach was to ensure the questions were clearly understood and to improve completeness, although participants were informed they could refuse to answer any question if they preferred not to give a response. Clarity was offered when needed. Typically, these instruments are used in an interview format. The CANDID can be completed by an adult with developmental and/or learning disability, a parent or care staff. All questionnaire data in this study were the responses of adults with ASD. Data previously collected and used in this study from the NIHR Transitions Study was from the wave 2 timeframe to ensure that it was the most recent information. Stage One also collected social and demographic information relating to the participant and their family. Family information collected at this stage was used to later recruit participants for the qualitative portion of this study. As stated in the study packet, following the data collection meeting in Stage One, a £25 gift voucher was given to the adult with ASD as a thank you for their time. Vouchers were not given to adults with ASD or their family members who participated at Stage Two.

## Quantitative data analysis

The software, Statistical Package for the Social Sciences (SPSS 22) was used to analyse quantitative data with descriptive and cross tabulations. First descriptive and inferential statistics of the sample were explored. Then bivariate associations using chi-square were applied. Data on support needs and service use were also described by age, due to the theoretical importance of this variable for this study. A  $p$  value of  $<.05$  was considered statistically significant.

The quantitative questionnaires answered by adults with ASD generated numerical and categorical data about their current needs, support provision and service use. The strength of the quantitative findings lies in answering the research questions about type and level of need, support provision and service use of adults with ASD. However, the quantitative data provide a limited self-reported snapshot of the current needs and support of adults with ASD. They

do not identify past experiences, needs or support, nor how needs are anticipated to be met in the future. Moreover, although they identify formal and informal support they do not detail by whom or how specifically support is provided, or the exchanges that occur within the social contexts they describe. Thus, qualitative semi-structured interviews were designed to contextualise the quantitative information collected in order to capture a comprehensive picture of need and support for adults with ASD, adding detail across time and from different individual perspectives. Additionally, the qualitative findings met the research objectives to explore family relationships, role changes, concerns, preferences and future expectations for support from the perspectives of parents, adults with ASD, their siblings and partners and to investigate family future support planning for an adult with ASD.

## **Stage Two: qualitative data collection**

### **Research questions**

The research questions addressed through semi-structured qualitative face to face interviews in this stage of the study were:

- (i) What are the needs of adults with ASD?
- (ii) How and by whom are their needs being met?
- (iii) What are the unmet needs of adults with ASD?
- (iv) What are the patterns of relationships, and interactions between family members of adults with ASD?
- (v) How are the needs of adults with ASD anticipated to be met in the future?

Although a number of these questions (i.e. (i) to (iii)) are repeated from Stage One, how, and of whom, these questions are asked differs in Stage Two to elicit multiple response perspectives. In addition, needs, socio-historic experiences and family relationships were explored retrospectively, currently and prospectively at this stage.

### **Sample**

A subsample was recruited from Stage One of 10 families from the younger age group of adults with ASD and 11 families from the older age group. The sample consisted of 49 people including: 21 adults with ASD (10 from age group 18-29 years and 11 from age group 30+ years of age), 16 parents, 4 partners and 8 siblings.

### **Sample recruitment and response**

The recruitment approach in the qualitative stage can be described as a snowball or network sample (Seale et al., 2004) as the potential respondents were gathered by those already in contact with the researcher as they fit the criteria for inclusion. In these sampling methods referrals are made by acquaintances or peers rather than through more formal methods of identification (Atkinson and Flint, 2001). This strategy can be used to overcome the problems associated with sampling populations who are difficult to access or to reach a target population (ibid). Recruitment for Stage Two began in August 2014 and continued until April 2015.

The recruitment of suitable candidates for Stage Two proceeded through initial contact with the adult with ASD in Stage One. In consultation with the adult with ASD, the willingness and ability of a parent, brother or sister, or partner were identified for further contact for Stage Two. Contact information for family members was collected in Stage One, when an adult with ASD expressed an interest and willingness for them to be asked to participate in Stage Two. Where an adult with ASD had more than one sibling, the adult with ASD identified who to ask to participate. Taking the adult with ASD's perspective of the ability and willingness of their parent, sibling or partner to participate in the interview process intended to avoid undue stress that may have resulted for some participants should recruitment have proceeded without this informed knowledge. Eleven older adults and five younger adults with ASD in Stage One, during the meeting with the researcher, identified their family members for contact to be asked to participate in Stage Two. Invitation packets, including a letter of invitation, an information sheet explaining the study, together with a contact form and a stamped addressed envelope for return to state their interest in participation, was sent by post to family members of these 16 autistic adults (see study packet documents in Appendix B).

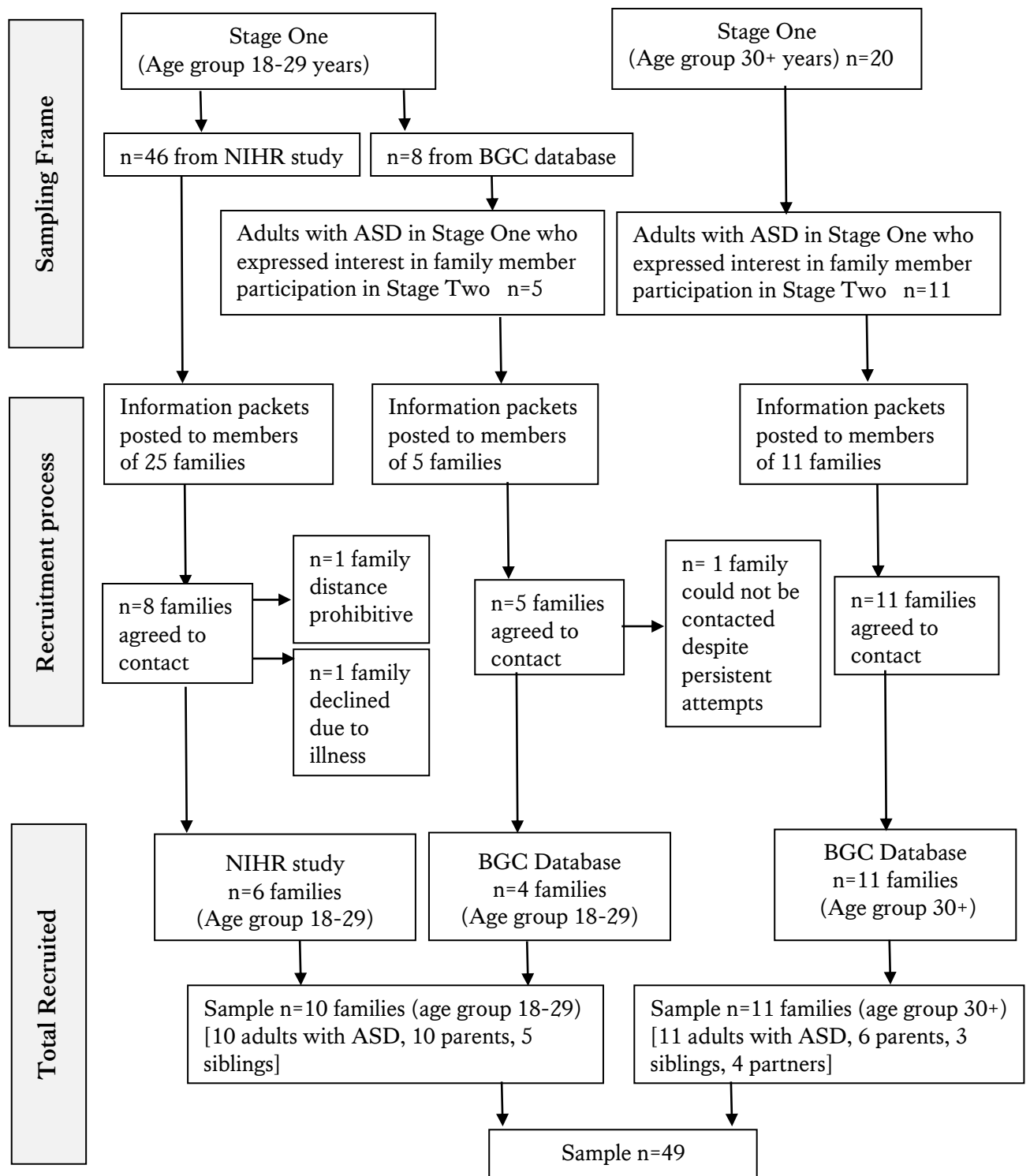
However, because the author had not personally interviewed many of the younger aged adults with ASD in Stage One, with data used for 46 participants from the NIHR Transitions Study, snowball sampling methods were not able to be applied to recruit all younger aged group family member participants for Stage Two. As such, recruitment for Stage Two family participants for some in the younger age group differed slightly from the process used to recruit family members of older adults with ASD and younger adults with ASD for whom the researcher conducted the quantitative data collection. Stage Two invitation packets were

sent to the household of 25 out of 46 randomly chosen younger adults with ASD whose quantitative information collected in the transition to adulthood study was included in Stage One (see Figure 5.2).

From the collective packet mailings, multiple family members of 13 younger, and 11 older adults with ASD accepted to be contacted for a further explanation of the study (see Figure 5.2). All those who had been identified by autistic adults in Stage One agreed to be contacted and subsequently to participate. One of the five younger age group family households identified for contact in Stage One could not be reached despite persistent attempts. Eight families from the NIHR study, who were unknown to the researcher, agreed to contact for further information about the study. No response was received from 17 households to whom packets were posted from the transition study.

Parent, partner and sibling recruitment proceeded from telephone contact following these acceptance acknowledgements. One younger age group family declined to participate because of illness, one could not be contacted despite persistent attempts and for one the travel distance was prohibitive to inclusion. The sample included 10 families of younger aged adults with ASD including: 10 adults with ASD, 10 parents, and 5 siblings; and 11 families of older adults with ASD including: 11 adults with ASD, 6 parents, 3 siblings and 4 partners.

Figure 5.2 Recruitment procedure flow chart: Stage Two



## Study site

All interviews were conducted in a place of the participant's choosing. All chose their own homes. Each participant was interviewed individually with no one else in the room, with the exclusion of partners. Although partners were interviewed individually, all interviews were conducted with the partner in the same room at the time of the interview.

## Qualitative research instruments

### *Interview guides*

For the qualitative stage of the study, an interview guide, consisting of semi-structured open ended questions and follow up probes guided the process of face to face interviews with the participants. Separate parent, sibling and partner guides were developed (see Appendix E).

The parent interview guide for the qualitative interview was adapted from an interview guide used to assess the effects of caregiving across the life course, the needs of ageing parents of dependent adult children with intellectual disability and their future plans for their adult child (Taggart et al., 2012). A minor adjustment replaced references to a person with a learning disability to an adult with ASD, while maintaining all topic questions and probes. Permission to use this guide was acquired from the authors. The parent was asked to describe their adult child with ASD in regards to severity of impairment, challenging behaviours, physical and mental abilities and health, level of independence and the types of support they require. They were asked if and how caregiving over the years had impacted their health and the types of, and their satisfaction with, the support services (formal and informal) they have used and currently use. How their role as carer has changed over the years, as well as their plans for the future care of their adult child was also explored (see Appendix E).

The partner interview guide maintained the same topic questions but was modified from the parent interview guide to explore the support roles and relationship of the adult with ASD and their partner (see Appendix E). It included questions about their relationship, health, and support provision. Support was explored from a bidirectional perspective with partners; that is, how they supported each other. The interview guide also investigated if any plans for future support were needed, and in place.



The adult sibling relationship and expectations for future support was explored from both the perspective of the adult with ASD and their sibling. The sibling guide was constructed using relevant literature on sibling relationships in adulthood (Campbell et al., 1999, Orsmond et al., 2009) and across the life course (Cicirelli, 2013, White, 2001), including siblings with and without disabilities, and in reference to the research questions. The interview guide for the adult with ASD and their sibling's interview was the same and included relationship questions that explored current sibling interactions and frequency of contact, how (if at all) the relationship has changed over the years and how they envisioned their future roles and relationship to be when their parents are no longer alive (see Appendix E). In addition it explored family communication about future support plans and the inclusion of the adult with ASD and their sibling in the discourse.

#### **Procedure**

Prior to beginning the interview, participants were reminded of the objectives of the study and asked if they had any questions. They read and signed a consent form (Appendix C) and it was reiterated that participation in the study was voluntary; they did not have to answer any question they preferred not to and that they could stop the interview at any time if they did not wish to continue. The relevant interview schedule (Appendix E) was followed as a general guide to direct the conversation and ensure all relevant topics were covered, although points of interest that arose in the interview were followed up by the researcher. All interviews were recorded using a digital recorder. Each participant was thanked for their time at the end of the interview and asked if they had any questions.

The interview consisted of three main parts. First the interviewer introduced herself, the study, the interview process and asked a few short closed ended questions to gain factual demographic information (i.e. age, qualifications, and living arrangement) about the participant. Additionally, this part developed a comfortable interaction. The second part included the 'interview' whereby the respondent was invited to talk about their experiences and perceptions relevant to the interview questions. The main responsibility of the researcher during this part was to listen and guide the respondent through a conversation using prompts where necessary until all important issues on the interview guide were explored. The third part of the interview consisted of a series of 'ending' questions designed to encourage the

respondent to add any information that they felt may have been missed during the interview and/or to expand on any topic. Additionally, the participant was thanked for their time and information.

### **Qualitative data analysis**

The computer software QSR NVIVO (2011) was used for storage and coding the interview transcripts (NVivo, 2011). Thematic analysis was used to analyse the qualitative data. The thematic analysis adopted a combination of inductive and deductive approaches. While primarily driven by data emerging from the Stage Two interviews, Stage One quantitative findings, the theoretical underpinning of the life course perspective and the research questions also influenced the qualitative data analyses. In particular, these features contributed to exploring why individuals have the support needs they do, how they experience, and had experienced, support, and the effects it has on the adults with ASD and their family members. Thematic analysis offered a flexible, simple approach to analysing the data from the semi-structured interviews, which is independent of theory but applicable across a range of theoretical approaches (Braun et al., 2014). Its ability to reflect reality and how it is constructed socially through the processes of identification, organisation, description and reporting of patterns within data was advantageous. Braun and Clarke's (2006) guidelines, as described below informed the thematic analysis in this study.

Immersion through reading and re-reading the transcripts provided familiarity with the data. All interview material was both hand coded and imported into NVivo for coding and analysis. The main benefits of using computer software were that the data could be searched and cross-examined easily using search words and links between interview data could be made. The codes were given meaningful names that gave an indication of the idea or concept. Codes were attached to a segment of text, namely a word, phrase, sentence or paragraph expressing feelings, perspectives, ideas and experiences (see excerpt of coded transcript in Appendix F). A large number of codes were initially identified which led to a further exploration of the relationship between them, how they captured something important and made sense of the data. Codes were sorted into categories (see Appendix F). Using this method all newly gathered data were continually compared with previously collected data and its coding in order to refine the development of the categories. Data analysis in this study proceeded

sequentially, enabling comparison of the completed quantitative data analysis with the qualitative data. This provided corroboration with quantitative findings and elaborated richer detail. As such, in the qualitative data analysis a priori, analytic and descriptive categories were developed. A priori categories broadly mapped onto the Stage One quantitative categories of general health, social relationships and general welfare. Analytic and descriptive categories included interactions, experiences and perspectives among participants to further answer the research questions. This approach complemented the research questions by facilitating an investigation of the interview data from a deductive data driven perspective and a perspective based on inductive coding. Categories were synthesised into themes by identifying significant patterns, gradually elaborating a small set of generalisations that incorporated the consistencies identified in the data (See appendix F). As a whole, the final themes focused on essential needs and support of adults with ASD, experiences, perspectives, priorities and family future support plans.

Although presented as a linear, step-by-step procedure, the research analysis was an iterative and reflexive process. As the interviews were exploratory and qualitative in nature, there were no hypotheses to be tested. In thematic analysis there is no aim to produce a theory of support need for adults with ASD, as is the purpose with other types of qualitative data analysis such as grounded theory (Braun and Clarke, 2006). Rather the intention is to allow research findings to emerge from dominant or significant themes inherent in the raw data, without the restraints imposed by structured methodologies (Vaismoradi et al. 2013).

One of the most basic means used to support quality and validity was the verbatim transcription of all interviews alongside the systematic use of participant quotes to provide evidence and transparency in the presentation of themes. The use of participant quotes also serves to provide information for readers to make their own judgments about the closeness of fit between themes and participant quotes (Creswell, 2013). An explicit description of the phenomena from the individual participants' perspective also allows for difference of experience and perception to be demonstrated between participants (Smith, 2015).

## **Ethical considerations**

The study was granted ethical approval by the NRES Committee London-Camberwell St Giles Research Ethics Committee in July 2013 (reference: 09/H0807/71) (see Appendix A). The study was also approved by the Institute of Psychiatry Research and Development Office. Participation in this research was entirely voluntary and no one was coerced or induced to participate. As stated in the invitation to participate thank you vouchers of £25 were given to participants in Stage One. Written informed consent prior to beginning the interview process was obtained by the researcher from each participant, after the study brief was presented and any questions the participant had were answered.

## **Distress**

As the topic is a sensitive, emotional subject it may have induced feelings of discomfort or distress for the participants. At a time in their lives when these parents may be experiencing declines in their own health and functional abilities, they have the added worry and concern for the support of their adult child with ASD. Discussing future plans and the inevitable transition of support may have caused feelings of fear, anxiety or denial for these parents, both regarding their own death and their worries for the future for their adult children with ASD. The nature of this topic may not be something family members have discussed either together or with others and it may have been disturbing to address it with a stranger. Likewise there was no therapeutic benefit to participants, but the study may have provided an opportunity for them to express their thoughts and feelings. Having such a discussion may have produced reflective thoughts on a lifetime of devotion and support. It may have highlighted for themselves the details of, or the need for, preparations for continuity of support for their adult children with ASD. The utmost care was taken to ensure no sense of judgement from the interviewer was perceived by the parent, partner, adult with ASD or sibling regarding their degree of future support planning. The researcher carried information on local counselling services should participants have requested such an intervention. No requests were made.

Participants were informed that they may choose to skip over questions they would prefer not to answer, and that they could terminate the interview at any time. A few participants declined to answer a question, but none terminated the interview. The interviewer was respectful of the participant's time and level of fatigue with the interview process.

### **Confidentiality and anonymity**

Rigorous procedures were used to protect confidentiality of the study data and the identity of the subjects. Audio recordings and transcriptions were securely stored on password encrypted files. The recording of the interview was erased as soon as it had been transcribed verbatim. All interviews were transcribed by the researcher. Participants were assigned a random numerical code on all documents to ensure anonymity. All paper documents were kept in a locked filing cabinet in a locked office, and no one other than the primary researcher had access to these. The participant's name or any information that could identify them was not kept with their research data.

### **Chapter summary**

This chapter described the research method design, the structure and process that were used in this study. It underscored that while the quantitative questionnaires provided an objective exploration and a view of the structural features of the support needs of adults with ASD, the qualitative interviews provided detail through the voice and perspectives of the lived experiences of adults with ASD, their parents, partners and sibling. The next four chapters present the results of the research process: Chapter 6 outlines the quantitative findings at Stage One and Chapters 7, 8 and 9 present the results of the in-depth semi-structured interviews at Stage Two.

## **Chapter 6: Quantitative findings: sample characteristics, support needs and service use**

This first of four findings chapters outlines key socio-demographic characteristics, and describes self-reported needs and service use of a sample of 74 adults with ASD who participated in Stage One of this study. As described in the Methods chapter, Stage One includes quantifiable information from questionnaires acquired in a face-to-face meeting with adults with ASD. The intention of this chapter is to answer the research questions, ‘What are the support needs of adults with ASD, how and by whom are they being met and what are their unmet needs? Additionally, it seeks to identify and quantify the self-reported service use of adults with ASD. It begins with relevant descriptive findings of socio-demographic characteristics of the sample, as well as comparisons between two age groups (18-29 and 30+ years of age). Findings of 54 adults with ASD are represented in the younger age group and 20 in the older age group. The chapter then identifies and describes the range of life domains in which participating adults with ASD report needs and the extent to which they are, or are not, being met through formal services and informal support. It also explores similarities and differences in need and support between the two age groups of adults with ASD. This study’s findings suggest that older adults with ASD have needs in more areas compared to younger adults with ASD, and that family are providing considerably more support to these older adults. Additionally, formal health service use within the last three months prior to their interview is also investigated and reported. The chapter concludes with a summary and discussion of key findings.

### **Statistical analyses**

Socio-demographic information, needs and service use data were analysed using both descriptive and inferential statistics, mainly percentage distributions for categorical data and means and standard deviations for continuous data and chi-square tests and t-tests to examine differences between age groups. The analysis focused on age related differences in the following key characteristics: needs, support provision, and recent health service use. As the CANDID is not normally distributed initial investigations for this indicator used the nonparametric Mann-Whitney U test to examine differences in needs and support provision.

Where results were significant, they were also examined using t-tests and, as the results were similar only t-tests are reported. Discussed are most prevalent domains of need, and those reaching statistical significance or approaching significance. However, as this is a purposive sample, it is not representative of the population of adults with ASD, and because it is small in size caution is required when interpreting the statistically significant values reported in this chapter. While values are not generalisable, they may offer a baseline of the support needs and differences between age groups of high functioning adults with ASD from which to conduct further research on a larger more comprehensive scale.

## **Sample**

Seventy-four adults diagnosed with ASD participated in this stage of the study. All participants were considered to be cognitively high functioning although IQ levels were not known for all participants. They all had good verbal communication and comprehension (Koyama et al., 2007). The ethnicity of the 74 participants was predominantly White or White British, with 3 Black, 1 Asian and 3 who reported 'Other'. While around half of the participants lived in Greater London, the remainder were spread throughout the counties of Kent, Essex, Hertfordshire, Bedfordshire, Surrey, Sussex and Yorkshire.

### **Representativeness of the sample**

The representativeness of the sample is difficult to determine based on limited epidemiological data for adults with ASD in England. Additionally, as only adults with autism considered to be high functioning and without a learning disability were chosen for participation it is not representative of the profile or support needs of adults across autism spectrum. Moreover, as this sample is composed primarily of those known to services it may not represent adults with ASD in the community who are not in contact with health or social services.

Statistical evidence reported from the 2014 Adult Psychiatric Morbidity Survey of the profile of ASD among adults living in the English household population and peer-reviewed empirical findings were used as a comparative framework to assess aspects of the representativeness of the sample findings throughout this chapter. The Adult Psychiatric Morbidity Survey is a random sampling of private households in England conducted every seven years to explore national mental health and wellbeing (Adult Psychiatric Morbidity Survey, 2014). The 2014

report detailed information and analyses on the prevalence of autism in the adult population (aged 16 and over), as well as the educational qualifications, IQ, employment status and treatment and service use of this population (Brugha et al. 2014). Additionally, where available, general population statistical evidence for demographic factors are provided for comparison to those of the current sample.

### **Defining the socio-demographic characteristics of the sample**

A range of socio-demographic characteristics of the sample are described in this section. Socio-demographic factors may influence the support and service needs of adults with ASD. For example, older age and decreased independence and unemployment may be reflected in higher levels of need, while younger age, employment, and having a partner may decrease need. Relevant demographic characteristics to this research include: age, sex, marital status, number of siblings, living arrangement and employment. Full demographic characteristics of participants are provided in Table 6.1. Additionally, Table 6.2 shows available information for each participant including: date of birth, gender, diagnosis, ADI-R, ADOS, AQ and IQ. Demographic characteristics illustrate that older participating adults with ASD have significantly higher levels of unemployment, are more likely to be living with a partner or alone, and have fewer siblings compared with younger adults with ASD. These are important factors to consider in planning and meeting future support needs. The availability of family support and employment may decrease the amount of future formal support and service needs as adults with ASD age.



Table 6.1 Socio-demographic characteristics of participants

Characteristic	Percentage value (%)	Raw Number values (n)	Adults with ASD 18-29 years (n)	Adults with ASD 30+ years (n)	Missing (n)
Mean age years (sd.)		27 (11.7)			0
18-29 year olds	73	54	25 (2.2)		0
30+ year olds,	27	20		45 (9.8)	0
Gender	85 Male 15 Female	63 Male 11 Female	48 male 6 female	15 male 5 female	0
Ethnicity					
White or White British	91	67	47	20	0
Black	4	3	3	0	0
Asian	1	1	1	0	0
Other	4	3	3	0	0
Living Arrangement					
Lives with both natural parents	35	26	25	1	0
Lives with natural mother	26	19	17	2	0
Lives with natural father	1	1	1	0	0
Lives with partner	8	6	0	6	0
Lives with relative	4	3	2	1	0
Lives with non-relative	7	5	3	2	0
Lives Alone	15	11	3	8	0
Other	4	3	3	0	0

Marital Status					
Never Married	91	67	54	13	0
Married	5	4	0	4	0
Cohabiting	3	2	0	2	0
Separated or divorced	1	1	0	1	0
Siblings					4
No siblings	16	11	5	6	
1 sibling	56	39	32	7	
2 siblings	16	11	7	4	
3+ siblings	13	9	7	2	
Education					
Not in education	64	48	28	20	0
In education	36	26	26	0	0
Full-time education	30	22	22	0	0
Part-time education	6	4	4	0	0
Statement of Special Education Needs	57	42	38	4	1
Employment					
Employed and not in education (incl. voluntary and part-time work)	27	20	15	5	0
Unemployed and not in education	73	54	37	17	0

Table 6.2 Participants date of birth, gender, and diagnostic information [should this just go in appendix]

Date of Birth	Gender	Diagnosis	ADI-R	ADOS	AQ (self)	IQ
02.04.51	M	AS, OCD, mild depression		(2,5,0,0)	46	
17.11.59	M	CHA	(16,17,5)		34	
24.11.62	M	HFA, depression		(6,10,2,4)	46	
22.07.62	F	AS, mild depression		(2,11,1,1)		(120,104,114)
23.08.63	M	AS, GAD		(4,16,1,1)		
28.03.64	M	AS, Anxiety	(7,13,4)	(7,14,2,6)		
16.09.67	M	AS, GAD		(5,14,1,3)		
07.05.68	M	HFA		(4,10,0,1)		(106,118,114)
11.08.69	M	CHA		(5,10,2,0)		
28.09.70	F	AS	(17,18,6)		35	(112,115,115)
18.11.71	M	AS, mixed anxiety depression		(3,10,1,0)		
20.03.73	M	AS	(5,14,3)			
19.05.74	M	AS, traits of OCD	(4,4,3)	(4,7,1,1,)		(104,116,110)
02.11.75	M	CHA		(3,10,1,1)		
28.09.76	F	AS, GAD, Hoarding disorder	(9,12,3)		41	
11.03.78	M	AS	(7,10,3)	(2,3,1,0)	41	(121,129,128)
06.06.79	F	HFA, GAD	(12,18,3)		45	
13.08.79	M	AS	(6,6,2)			
09.19.80	M	AS, social anxiety		(2,8,0,2)	41	
17.06.81	F	AS, depression, GAD		(5,3,0,3)		
12.05.86	M	ASD	Yes	Yes	37	
02.10.86	M	AS	No	Yes	35	
20.01.87	M	ASD	No	Yes	26	
08.02.87	M	AS	Yes		28	
19.07.88	M	AS and ADHD	No	Yes	33	
18.01.88	M	AS	No	Yes		
23.09.88	M	CHA	Yes		29	
30.09.88	M	AS, ADHD	Yes	Yes	33	

Date of Birth	Gender	Diagnosis	ADI-R	ADOS	AQ (self)	IQ
04.08.88	M	ASD	Yes	unknown	27	
16.01.89	F	ASD	Yes			
09.01.89	F	HFA	Yes	unknown	28	
07.12.89	M	ASD	Yes	Yes		
03.03.90	M	AS	Yes	unknown	38	
24.07.90	M	HFA	Yes	Yes	33	
13.11.90	M	AS	No	Yes	38	
02.10.90	M	AS	Yes	unknown	45	
17.04.90	M	CHA, Dyspraxia	Yes	Yes	42	
24.11.90	M	AS	No	Yes	28	
15.12.90	M	ASD	Yes		35	
07.12.91	F	ASD and ADD	No	Yes	32	
30.03.91	M	AS	Yes		43	
03.05.91	M	AS, Dyspraxia	Yes	Yes	40	
02.02.91	M	HFA	Yes	Unknown		
21.08.91	M	HFA	Yes	Unknown	34	
30.08.91	M	ASD, Dyspraxia		Yes		
03.11.91	M	AS	No	Yes	37	
25.02.91	M	HFA, ADHD, Tourette's	Yes	No		
02.04.91	F	AS	No	Yes		
05.12.91	M	ASD	Yes		37	
15.03.92	M	AS	Yes	No	40	
21.05.92	M	HFA	Yes	Yes	26	
05.10.92	M	ASD, epilepsy	Yes	No	43	
11.09.92	M	CHA	Yes	Yes	34	
10.06.92	F	CHA	Yes	No	44	
03.01.92	M	AS, Dyspraxia	Yes		37	
05.12.92	M	ASD	Yes		35	
11.04.92	M	AS	Yes	Unknown	38	
22.11.92	M	AS	Yes		25	
23.05.93	M	ASD, mixed anxiety & depression	Yes	Yes	32	normal

Date of Birth	Gender	Diagnosis	ADI-R	ADOS	AQ (self)	IQ
16.03.93	M	ASD		Yes	42	
18.05.93	M	AS	Yes	No		
01.05.93	M	AS	No	Yes	38	
29.12.93	F	HFA	Yes	Yes		normal
07.11.93	M	ASD	Yes			
16.03.93	M	ASD, OCD	Yes	Yes	42	
03.09.93	M	CHA	Yes			
19.08.93	M	AS	Yes			
22.01.93	M	ASD		Yes	28	
16.08.95	M	ASD, ADHD	No	Yes		
31.10.94	M	ASD	Yes			
29.07.94	M	ASD	Yes			
06.03.94	M	ASD, Epilepsy	Yes			
14.01.94	M	ASD	Yes			
21.05.95	M	ASD, mild anxiety & depression	Yes	Yes		normal

Asperger's Syndrome (AS), High functioning autism (HFA), Childhood autism (CHA), Autism Spectrum Disorder (ASD), Obsessive compulsive disorder (OCD), General Anxiety Disorder (GAD), Attention Deficit Hyperactivity Disorder (ADHD).

### Age and sex

In Stage One the ages of the 74 participating adults with ASD ranged from 19 to 65 years with a median age of 25 years (interquartile range 23-35.8). The younger age group (18-29 years) consisted of 54 participants; 20 were in the older age group (30+ years). The sample comprised 63 men and 11 women with male to female ratio of 6:1 (see Table 6.1). The higher proportion of males in this study is consistent with epidemiological findings of the uneven sex ratio in autism (Mandy et al., 2012). Previous research reports a 4:1 male to female ratio across the whole autism spectrum (Baird et al., 2006, Fombonne, 2003, Fombonne, 2009) increasing to 8 or 9 to 1 in higher functioning samples (Mandy et al., 2011, 2012) In this sample female participants in the older age group were represented at a ratio of 4:1 (15 men and 5 women) consistent with the ratio across the spectrum, while the male to female ratio in the younger group is consistent with the higher functioning ratio of 9:1 where 48 out of 54 participants were men.

### **Diagnosis**

As can be seen in Table 6.2, the diagnostic composition of participants included: 34 Asperger's Syndrome, 8 Childhood Autism, 13 High Functioning Autism and 22 with the diagnosis of ASD. All four diagnostic categories were represented by participating males and females. Measures of severity of autistic features (AQ scores) imply that the traits of most participants met a clinical level of autism. The level of cognitive functioning (IQ level) were unknown for the majority of participants, only for 5 out of 74 (see Table 6.2). The adults with ASD in this sample were relatively 'high functioning'. All were fluently verbal and had mental capacity to consent to participate. Next, the marital status of the participants is described.

### **Marital status**

Limited research has explored marriage and cohabiting relationships of people with autism. Nearly all (n=67, 89%) of the adults with ASD who participated in this study were never-married. This corresponds with findings from the 2007 Adult Psychiatric Morbidity survey in England in which people who were never-married were more likely to be assessed with autism than people of all other marital statuses combined (Brugha et al. 2009). The 2011 Census identified the marital status of adults 16 years of age and older living in the UK as 51% married, 35% never-married (i.e. that had never been in a civil partnership), 10% living as part of a cohabiting couple, 9% divorced and almost 3% separated (Office for National Statistics, 2016). This sample of adults with ASD presents contrasting marital status in comparison with adults in the general population with only four participants (20%) married, one divorced (5%) and two cohabitating (10%) in the older age group. None of the participants in the younger age group reported being married or in a cohabiting relationship at the time of the interview. These findings are similar to previous studies which report that only 5–10% of adults with ASD marry or have long-term sexual relationships (Eaves and Ho, 2008, Howlin et al., 2004). The low rate of marriage and parenthood in adults with ASD excludes reliance on a spouse or children for support in older age (Piven and Rabins, 2011). However, for those participants in long-term relationships, partners seemed to replace parent and sibling assistance, providing emotional and functional support in many ways (see Chapter 8). Persisting social and communication difficulties associated with ASD (Seltzer et al., 2004) and challenges in forming intimate bonds (Marriage et al., 2009) may contribute to the large

majority of sample participants being never-married. Yet, marital status does not necessarily identify living arrangements, which will be discussed next.

### **Living Arrangement**

At the time of the interview almost two thirds (n=46, 62%) of the sample were living with one or both parents. As, expected, more in the older age group (n=14, 70%) in comparison to the younger age group (n=3, 5%), were living alone or with partners. Previous research has reported a range of 50–60% of adults with ASD still live with their parents or in sheltered residential placements (Beadle-Brown et al., 2006, Levy and Perry, 2011). Additionally, 17 participants (23%) were living alone or with a partner, and 11 (15%) in other types of living arrangements, including residential accommodation and living with others, such as relatives other than parents and non-relatives. The Office for National Statistics (ONS) (2014) reported 26% of adults between the ages of 20 and 34 in the UK were living with parents in 2013. Thus the rate of 62% living with a parent in the sample of adults with ASD is high compared with the general population. Moreover the ONS states that the percentage of adults living with parents decreases with age, with only 2% of people aged 35 to 64 residing with parents (Office for National Statistics, 2014). Among the older participants (aged 30+) in this study, 3 (15%) individuals continued to live with a parent, again a higher percentage than the national level. The high level of adults with ASD in this sample currently living with parents may foreshadow increased need for future accommodations when parents are no longer able to maintain this support. As discussed in Chapter 4, parents of adults with ASD may not be able to depend on a sibling to assume support responsibilities for their brother or sister with ASD in the future.

### **Siblings**

Being a sibling of a brother or sister with ASD does not end with adulthood. Sibling relationships, interactions and support often continues across the life course (Orsmond and Seltzer, 2007a). As discussed in Chapter 4, support responsibilities for a brother or sister with ASD may be assumed by a sibling post-parental care. However, some adults with ASD may not have a sibling; siblings may not be willing or able to provide support; and an adult with ASD may not need or want their sibling's support. To explore family future support potential, the number of siblings of the sample participants was recorded. The median number of siblings was 1 with a range of 0-5. More than half of participating adults with ASD had one sibling

(n=39, 56%), 11 participants (16%) had no siblings, the same number (n=11) had two siblings, with 9 participants (13%) having 3 or more siblings. Specifically, a greater number of adults in the older age group were only children (n=6, 33%) compared to younger adults, and most of the adults in the younger age group had only one sibling (n=32, 60%). This may have implications for the availability of future family support for this group and is discussed in greater detail in Chapter 9.

### **Employment**

The Office for National Statistics (ONS) reported the prevalence of unemployment in the UK for adults between the ages of 16 and 64 in May 2015 to be 6% (Office for National Statistics, 2015). A survey by the National Autistic Society (NAS) in the UK reported that only 15% of adults of working age with ASD are in full-time paid employment (Redman, 2009). The sample in the current study is consistent with the findings of low levels of educational qualifications and employment rates among adults with ASD in the Adult Psychiatric Morbidity Survey (Brugha et al. 2014). The unemployment level of adults with ASD (aged 18-65) in this sample was 73%, with 54 participants reporting being unemployed at the time of interview. Comparative analysis by age group found 85% (n=17) of the older participants and 69% (n=37) of the younger age group were unemployed ( $X^2=1.2, p=0.27$ ). Of the 37 in the younger age group who were unemployed, 22 (59%) were still in education which may account for their high unemployment level. However, similar patterns of low levels of employment have been reported in previous research with unemployment rates for adults with ASD ranging from 45-80% (Eaves and Ho, 2008, Howlin et al., 2004, Taylor and Seltzer, 2011). Moreover, Griffith and colleagues (2012) suggest that employment difficulties compounded by bad experiences may increase unemployment rates as adults with ASD age. Support in gaining and maintaining employment remains a crucial need for adults with ASD (Howlin et al., 2005), and unemployment may impact an adult with ASD's ability to achieve independent living (Howlin et al., 2004).

In summary, although there are a greater number of younger aged participants, the sample composition is broadly in keeping with previously observed sex differences in ASD (Mandy et al., 2011, Mandy et al., 2012). The living arrangements and employment prevalence for the study participants are markedly different to that of the general population, as expected.



Adults with ASD have higher rates of unemployment and remain living in the family home for longer than their peers without ASD. Moreover, specific differences in these areas are found between older and younger adults with ASD in this sample. A greater number of older adult participants live alone or with a partner and are unemployed compared with younger participants, who more commonly live with their parents and are still in education. Family composition shows the majority of sample participants have only one sibling, and that more older participants than younger ones are only children. All of these characteristics may impact the needs of these adults with ASD and how they are being met.

### **What are the needs of adults with ASD?**

This section focuses on the needs of adults with ASD reported by participants based on the CANDID (Xenitidis, 2003). As noted in Chapter 5, the CANDID assesses needs across 25 domains covering a broad range of social, mental health and physical health care needs. This study partitioned the domains into three categories for clarity of analysis and discussion: general health; general welfare; and relationships (see Figure 6.4). General health includes the eight domains of physical and mental wellbeing. The category of general welfare covers basic needs of food, accommodation and safety, including personal and financial security. Ten CANDID domains comprise this category. The remaining seven CANDID domains of need designated to the relationship category are associated with interpersonal interactions, opportunities and social abilities. The areas of greatest need expressed by adults with ASD in this sample are represented in each of these categories. Although no previous research has separated the CANDID domains into these categories, it was perceived doing so would provide an inclusive and clear picture of the needs of adults with ASD.

The section begins by presenting an overall description of need reported by participants. Thereafter it describes key individual areas of need based on the total sample and a comparative analysis of needs by the two age groups within each of the three overarching categories. The section continues with an investigation of met needs and to what extent needs are being met by services and informal support as identified in the CANDID. It concludes by exploring the unmet needs of the study participants.

### What is the level of need in adults with ASD?

As shown in Table 6.3, adults with ASD in this study reported high levels of need; reported are the mean, standard deviation and t-test significance as two-tailed possibilities (at a p value of <.05) for total need, met need and unmet need by age group. Participants had an average of 7.1 (sd. 4.5) needs in total out of a possible 25 domains, with 4.4 being met and 2.7 being unmet. Moreover, findings show a significant difference by age in total, met and unmet need. Older participants had a significantly greater number of domains in which they required help, had their needs met, and where needs were not met compared to the younger participants.

**Table 6.3 Mean number of total, met and unmet needs by age group**

<b>CANDID (potential range 0-25)</b>	<b>Total sample</b>	<b>18-29 years (n=54)</b>	<b>30+ years (n=20)</b>	<b>t-test Significance</b>
Total needs	7.1 (4.5)	6.0 (3.8)	10.7 (4.5)	-4.2, $p < .001$
Met needs	4.4 (2.9)	3.8 (2.6)	6.2 (2.9)	-2.3, $p = .003$
Unmet needs	2.7 (3.0)	2.1 (2.3)	4.6 (4.0)	-2.6, $p = .017$

Although age alone does not determine whether or not people have higher support needs, in older age people may have greater requirements for health, social, psychological and various other support services, including accommodation, recreation and leisure, mobility, finance, advocacy and family support (Coulton and Frost, 1982). Thus with normative age-related changes, the support needs of adults with ASD may increase similarly to people aging without autism. However, the higher needs expressed by older adults with ASD may also be suggestive of life course perspectives of historical time, in that the limited support and autism awareness they may have experienced growing up may have resulted in higher needs in older age. Moreover, adults ageing with ASD may also have additional support needs (Piven and Rabins, 2011) including but not limited to comorbidities of mental health, inflexible behaviours, heightened sensitivities and difficulty with change, that require consideration in future support planning. The next section identifies individual needs that indicate areas of support particular to adults ageing with ASD.

### What are the areas of need in the total sample?

Figure 6.1 shows total sample needs by domain within the three central categories of general health, general welfare and relationships. The four highest areas of need reported by more than half of the sample are *other mental health problems*, *money budgeting*, *welfare benefits* and *social relationships*. Assessing, recognising and meeting these and other important areas of need for adults with ASD may not only affect their wellbeing and quality of life now, but also ensure their security and dignity in the future.

#### *Category 1: General Health*

In the need category of general health, mental health needs markedly exceeded reported physical health needs. The CANDID question pertaining to the domain *other mental health problems* asks, “Does the person suffer from current psychological distress, anxiety or depression?” In this sample 51% (n=38) reported a need in this domain. As described in Chapter 4, ASD is highly comorbid with other psychological conditions. Previous research suggests rates of psychopathology in the range of 50-80% in adults with ASD (Fombonne, 2012, Ghaziuddin and Zafar, 2008). Additionally, poor mental health has been associated with unemployment, such that people with mental illness have significantly higher rates of unemployment (Baron and Salzer, 2002), and conversely that unemployment impairs mental health (Paul and Moser, 2009). The high rate of unemployment reported by adults with ASD in this study may be associated with the high need in the *other mental health problem* domain.

More than one third (36%, n=27) of participants stated having a *general physical health* need. This is noteworthy for both current and future support planning for adults with ASD, as they may require support in arranging, attending and following directives of medical appointments, accommodations of time and environment to adequately communicate physical concerns; and reminders for routine and preventative examinations. Thirty participants (40%) reported a need in the area of *eyesight/hearing*, and one quarter (n=19) of the sample had self-care needs. Limited understanding of social context, sensitivities, and poor organisational skills, may be challenges adults with ASD experience in the domain of self-care. Intervention strategies and future assistance may be required to enable adults with ASD to maintain self-care if currently parents are providing prompting or support in this area. A small percentage (5%, n=4) of sample participants expressed a need with each domain of substance misuse, mobility, and seizures. Although research has reported a 22-30% rate of seizures in

individuals with autism (Theoharides and Zhang, 2011), this sample presented a much lower prevalence. However, limited research investigating substance misuse and ASD seems to corroborate the findings of a low prevalence of need in this area (Chaplin et al., 2011, Murphy, 2003). Four younger adults with ASD reported difficulty using public transport, primarily related to anxiety and sensory sensitivities. One older adult with ASD expressed having physical trouble with mobility and used an electric mobility scooter outside of the home.

### *Category 2: General Welfare*

As shown in Figure 6.3 the need for financial welfare in the areas of *welfare benefits* (n=38, 51%) and *money management* (n=39, 53%) were reported by more than half of the sample. As previously reported, sample participants had difficulty finding and maintaining a job, reflected in the high levels of unemployment, which may account for some of the need in this domain. For security and wellbeing, it is essential that adults with ASD receive all of the benefits to which they are entitled to. However, some may not meet benefit criteria, be unaware of how to access benefits, and/or have difficulty completing the necessary paperwork. Although the 2007 Adult Psychiatric Morbidity Survey did not find more adults with ASD to be receiving state financial benefits than adults without ASD, they did discover that many adults with ASD did not know if they were receiving financial benefits which may indicate they are not managing (or be able to manage), their finances (National Health Service, 2009). In keeping with previous research, considerable difficulty in handling and managing money was expressed by participating adults with ASD (Mesibov and Shea, 1980). This is an area of concern that requires important consideration, as limitations in managing money and understanding finances may have detrimental consequences, such as the inability to purchase essential requirements, termination of services, legal repercussions, or financial exploitation. Future support in this area may need to be carefully prepared and planned for when family assistance is unavailable.

Exploitation risk was a need expressed by 29 (39%) participants of the sample, figures that are similar to those reported by Balfe and Tantam (2010) in their study of the social and health profile of adolescent and adults with Asperger syndrome. Exploitation may occur in financial or social contexts. As discussed in Chapter 9, some participant's recounted experiences of financial exploitation, having given strangers their personal banking information, and having

felt pressured to make unnecessary purchases. Others reported being taken advantage of in interpersonal relationships and not being able to recognise who is a friend. Tantam (2012) describes the issue of exploitation by ‘so-called’ friends of an adult with Asperger’s syndrome. Limited social and communication skills and a desire for social relationships may make adults with ASD particularly susceptible to counterfeit friendship and exploitation or abuse. Moreover, increasing independence and reduced service provision for adults with ASD are likely to increase the risks (Andrew Landman, 2014). The security and safety of adults with ASD may be compromised if they are unable to recognise or protect themselves from abusive or exploitative situations. Additionally 12 participants (16%) reported a need in the area of *safety of self* which also may be related to placing themselves in harm’s way or physically harming themselves. And finally, although a need in the domain of accommodation was reported by only 5% (n=4) of the sample this need may be much higher in the future for adults with ASD who are currently still residing with their parents. Where will these individuals reside when their parents can no longer accommodate them? Will they need an alternative residence, and if so, would it be with or without support?

### *Category 3: Relationships*

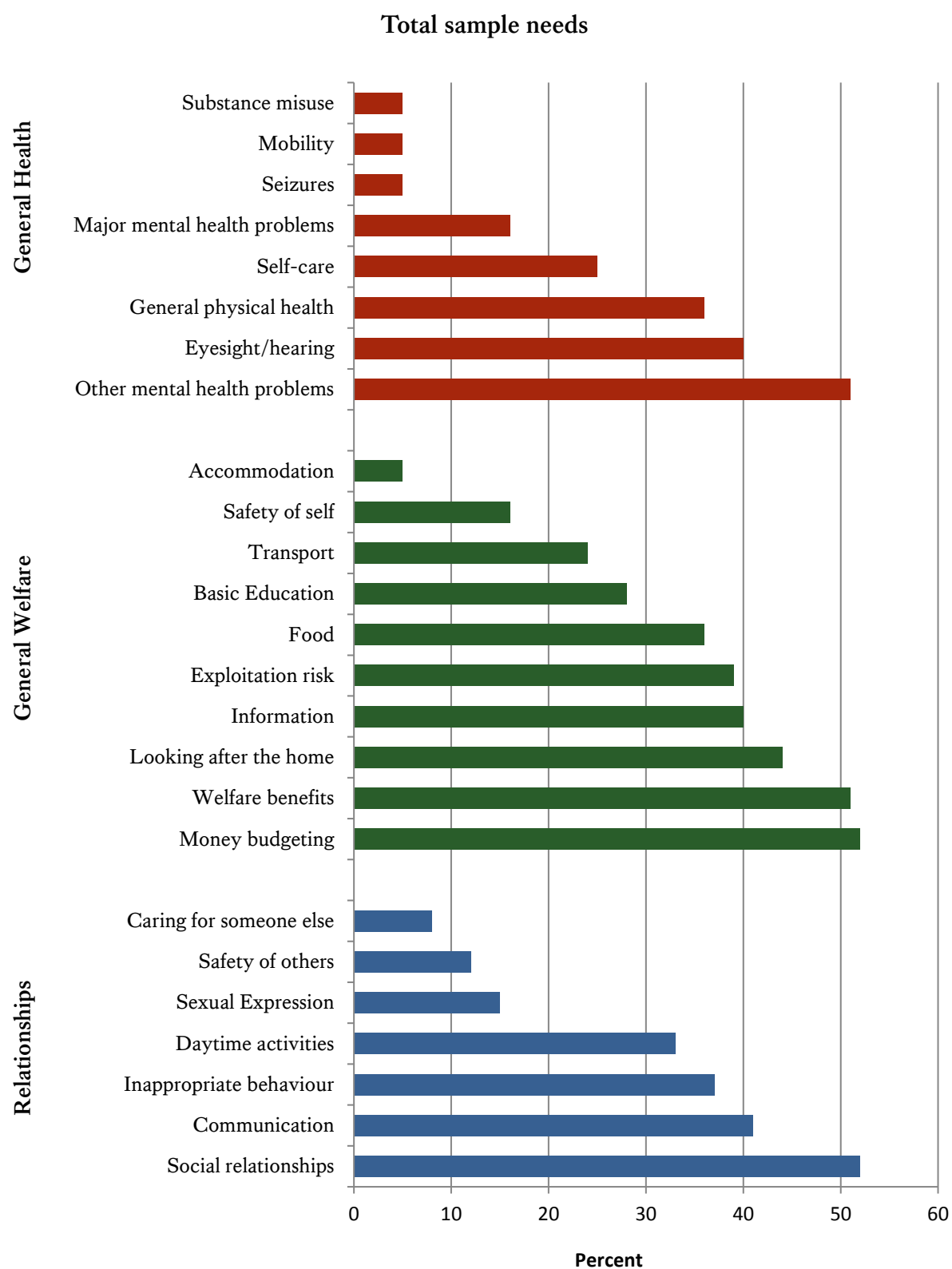
One of the greatest needs expressed by sample participants was in the area of *social relationships* (n=39, 53%). As explained in Chapter 4, difficulty with social cognition is a core symptom of autism, thus it is not surprising that the need for help with making and maintaining social contact is high in this sample. Previous research has reported low prevalence levels of friendships, peer relationships, and participating in social and recreational activities in adolescents and adults with ASD (Orsmond et al., 2004). Moreover, the CANDID question ‘Does the person have difficulty with regular, appropriate daytime activities?’ was answered as an area of need for a third of the sample (33%, n=25). This finding supports the results of a previous study which reported 20% of adults with ASD described having no activity during the day (Balfe and Tantam, 2010). High unemployment and few social relationships may also contribute to this need. Moreover, limited social relationships and opportunities for social interactions may place adults with ASD at risk of isolation.

Two other noteworthy, although not surprising, domains of high need in the relationship category include: *communication*, and *inappropriate behaviour*; both core features of autism. Almost half of the sample (n= 31, 42%) expressed a need in the area of communication. These

findings echo those of previous studies that have examined the communication and social difficulties faced by adults with ASD (Hofvander et al., 2009, Sperry and Mesibov, 2005). The inability to understand others or make themselves understood may heighten the risk of vulnerability and social isolation for adults with ASD. Communication difficulties have been identified as a risk factor of abuse, neglect and exploitation (Government, 2014, Lindsay et al., 2008). Social communication difficulties and social skill deficits may make it hard for adults with ASD to understand social cues, interact with others and understand consequences (Church et al., 2000), and difficult to develop social relationships. Somewhat fewer participants (n=28, 37%) reported a need in the area of *inappropriate behaviour*. As described in Chapter 1 repetitive ways of thinking and behaving seen in people with autism may be considered inappropriate. There is less societal tolerance and allowance for inappropriate behaviour in autistic adults than for children with ASD (Graetz, 2010, Robertson, 2009). Moreover inappropriate behaviour displayed by adults with ASD may jeopardise their safety and relationships. For example, one adult with ASD was physically beaten by a man on public transport for inappropriate behaviour directed towards a woman.

To summarise so far, the findings of the total sample suggest adults with ASD have high levels of need within the categories of general health, welfare and relationships. Current urgencies of need, and areas of concerns for future support, identified by more than half of the sample included psychological health, financial security and interpersonal relationships. In addition, lifelong challenges and high needs in communication and behaviour may place adults with ASD at risk of being exploited or harmed. Furthermore, areas of need that may be presently met by family members such as accommodation, food and self-care, could be heightened areas of future need and formal support when family provisions are not available. The next section will explore if there are age differences in need among adults with ASD.

Figure 6.1 Total sample needs by domain and category



### How do needs compare by age group?

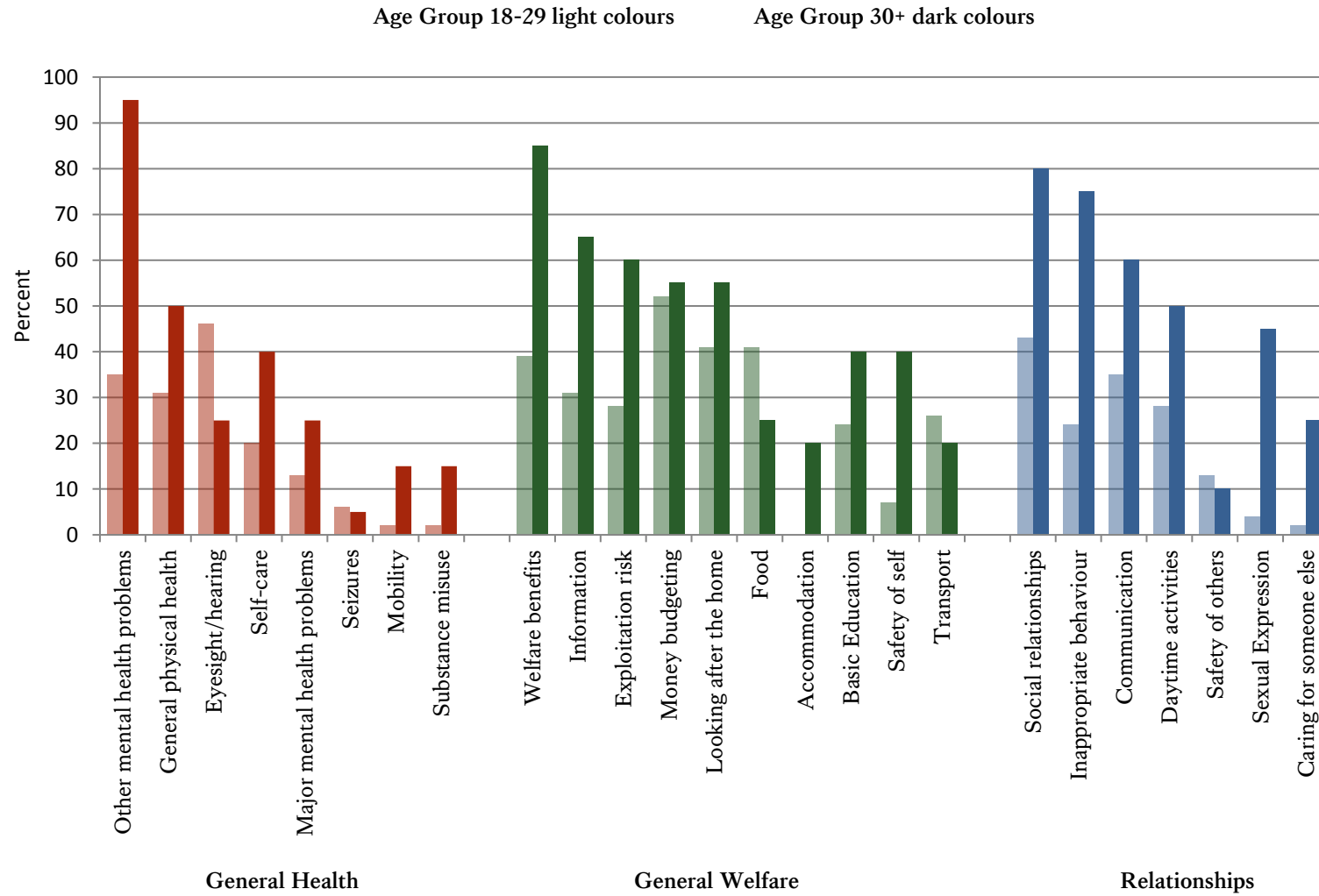
Although research is beginning to report the needs of adults with ASD, age differences in need remain largely unexplored. As described in the research methods, Chapter 5, the sample was divided into two age groups (18-29 years of age and 30 years and older) to explore similarities and differences. This section describes areas of need identified by the CANDID as reported by participants in each of these age groups. The findings suggest that areas of need and level of need vary by age. Although common areas of need were reported among all participants, few similarities in level of need were reported between the two age groups.

Figure 6.2 shows the CANDID distribution of need reported by participants' by age group. It clearly illustrates that in almost all areas, older participants reported greater need than younger participants. This difference may suggest experiential, situational, and/or age-related increases in need. Additionally the difference may reflect a higher recognition of need by older participants.

Table 6.4 shows the distribution of need across the 25 domains in descending order based on the total sample. It also includes the corresponding need for each domain in the two age groups and where significant, the Chi-square is reported. Noticeably, significant differences are recorded by age group in 11 domains of need. While younger participants reported the highest needs in the areas of *money budgeting, social relationships, looking after the home and welfare benefits*, older participants expressed highest need in the domains of *other mental health problems, welfare benefits, social relationships and inappropriate behaviour*. Figure 6.4 visually represents this data to show categories and domains of need in descending order. Figure 6.4 and Table 6.7 will be used to examine and describe how the needs of adults with ASD compare between age groups.



Figure 6.3 Percentage of need by age group, domain and category



**Table 6.4 Prevalence of needs according to the 25 life domains in the CANDID**

Area of Support Need	Total Sample n (%)	Age group 18-29 n (%)	Age group 30+ n (%)	Chi-square Significance
Social relationships	39 (53%)	23 (43%)	16 (80%)	$X^2=7.1, p=.008$
Money budgeting	39 (53%)	28 (52%)	11 (55%)	Not significant
Other mental health problems	38 (52%)	19 (35%)	19 (95%)	$X^2=17.6, p<.001$
Welfare benefits	38 (52%)	21 (39%)	17 (85%)	$X^2=5.8, p=.016$
Looking after the home	33 (45%)	22 (41%)	11 (55%)	Not significant
Communication	31 (42%)	19 (35%)	12 (60%)	Not significant
Information	30 (41%)	17 (31%)	13 (65%)	$X^2=5.0, p=.025$
Eyesight/hearing	30 (41%)	25 (46%)	5 (25%)	Not significant
Exploitation risk	29 (39%)	17 (31%)	12 (60%)	$X^2=4.2, p=.040$
Inappropriate behaviour	28 (38%)	13 (24%)	15 (75%)	$X^2=13.8, p<.001$
General physical health	27 (36%)	17 (31%)	10 (50%)	Not significant
Food	27 (36%)	22 (41%)	5 (25%)	Not significant
Daytime activities	25 (34%)	15 (28%)	10 (50%)	Not significant
Basic education	21 (28%)	13 (24%)	8 (40%)	Not significant
Self-care	19 (26%)	11 (20%)	8 (40%)	Not significant
Transport	18 (24%)	14 (26%)	4 (20%)	Not significant
Safety of self	12 (16%)	4 (7%)	8 (40%)	$X^2=10.3, p=.001$
Major mental health problems	12 (16%)	7(13%)	5 (25%)	Not significant
Sexual expression	11 (15%)	2 (4%)	9 (45%)	$X^2=20.6, p<.001$
Safety of others	9 (12%)	7(13%)	2 (10%)	Not significant
Caring for someone else	6 (8%)	1 (2%)	5 (25%)	$X^2=9.8, p=.002$
Accommodation	4 (5%)	0 (0)	4 (20%)	$X^2=11.4, p=.001$
Mobility	4 (5%)	1 (2%)	3 (15%)	Not significant
Seizures	4 (5%)	3 (6%)	1 (5%)	Not significant
Substance misuse	4 (5%)	1 (2%)	3 (15%)	$X^2=4.6, p=.032$

### *Category 1: General Health*

As described previously, the domain of *other mental health problems* was an area of need reported by more than half of participants. A Chi-square test of independence was performed to examine the relationship between *other mental health problems* and age. The relationship between these variables was significant ( $X^2=17.6$ ,  $p<.001$ ). Almost all older participants ( $n=19$ , 95%) stated they currently suffered with psychological distress, anxiety or depression, compared with just over a third of younger participants ( $n=19$ , 35%) reporting a need in this area. Factors of life course differences, situational context and ageing may be associated with this finding. Moreover, it may also be associated with the recruitment source, the Behavioural Genetics Clinic and the Department of Forensic and Neurodevelopmental Sciences. Mental illness is not a normative aspect of ageing, but factors such as physical decline and psychosocial adversity associated with ageing may increase the risk of poor mental health in older age (Alexopoulos, 2005). Older adults with ASD may experience elements of psychosocial adversity including unemployment, economic impoverishment, bereavement, loneliness and isolation that can increase the risk of mental illness. Indeed, a higher proportion of older participants were unemployed and living alone. Additionally, for older adults with ASD, being undiagnosed or misdiagnosed, coupled with limited support in early life stages may have contributed to the high levels of need in mental health reported in this age group.

As adults with ASD age they face normative age-related changes, as such 50% ( $n=10$ ) of the older age participants reported support need with *general physical health* compared with 31% ( $n=17$ ) of the younger group. As discussed in Chapter 4, adults with ASD may have difficulty communicating physical needs and symptoms. Health promotion, routine assessments and monitoring of physical and mental health as adults with ASD age may need to be initiated by informal or formal support services.

Although the difference in need in the domain of self-care between age groups was not statistically significant, twice as many older ( $n=11$ , 40%) than younger participants ( $n=8$ , 20%) reported needing help in this area. Support with self-care is essential to general health and may need to be considered in individualised future support plans for adults with ASD.

### *Category 2: Welfare*

In the domain of *welfare benefits*, older participants reported a significantly ( $X^2=5.8, p=.016$ ) greater need ( $n=17, 85\%$ ) compared with younger participants ( $n=21, 39\%$ ). The expressed need for welfare benefits among adults with ASD may signify that they are not receiving benefits or that they require more than they currently receive. The heightened need for welfare benefits reported by older participants is of great concern for their current and future wellbeing and requires further investigation.

*Money budgeting* was one of the few domains in which adults with ASD in both age groups reported a similar level of need. Managing money and paying bills was a high area of need for younger ( $n=28, 52\%$ ) and older ( $n=11, 55\%$ ) participants. This is an area that requires greater attention and support. Difficulty with money budgeting may present a challenge to independent living with informal or formal arrangements for guidance necessary.

Twelve out of twenty (60%) older participants reported a need in the area of *risk of exploitation*, a significantly ( $X^2=4.2, p=.040$ ) greater need than younger participants ( $n=17, 31\%$ ). Having fewer social supports, cognitive deficits, the inability to manage one's own finances and difficulties with activities of daily living has been shown to place elderly individuals at a greater risk of abuse and exploitation (Choi and Mayer, 2000). As autistic adults age they may experience some or all of these risk factors, with support necessary to ensure their security. Moreover *safety of self* was an area of heightened need. Older adults reported being more likely to have thoughts of self-harm or placing themselves in harm's way ( $n=8, 40\%$ ) compared with younger adults with ASD ( $n=4, 7\%$ ). The significant difference in need in these domains is a worry for the safety of older adults with ASD both currently and for the future when levels of family support may be diminished.

Although only four participants expressed a need in the domain of *accommodation*, all were in the older age group ( $n=4, 20\%$ ). The concern that accommodation needs may increase with age for adults with ASD emphasises the importance of future support planning. The lack of appropriate housing can have negative consequences for the health and security of adults with ASD (Totsika et al., 2010). Findings in the category of relationships are subsequently presented.

### *Category 3: Relationships*

A need in the domain of *social relationships* is a top priority for all participants; however, it is significantly greater ( $X^2=7.1$ ,  $p=.008$ ) in the older age group ( $n=16$ , 80%) compared to the younger age group ( $n=23$ , 43%). This difference may underscore disparities associated with life course support provision, situational context, or ageing. Early diagnosis and educational interventions for ASD have been shown to positively affect social abilities and outcomes in later life (Robins et al., 2001). All younger participants received a diagnosis of ASD before the age of 16 (criteria used in previous study), whereas the average age of diagnosis in the older group was 35 years old. When these older participants were children, primarily in the 1970s and 80s, recognising and diagnosing autism was less common than it was in the 1990s and onward when the younger participants were children (Grinker, 2008, Herbert et al., 2002). Additionally, support provision was more limited prior to 1990; 80% ( $n=16$ ) in the older group did not have a Special Education Needs (SEN) assessment at school compared with 28% ( $n=15$ ) in the younger group. The late age at which older participants were diagnosed, and limited educational support may be associated with their higher need in the domain of social relationships. Difficulty making and maintaining relationships may also be associated with the adult with ASD's living arrangements. A greater number of older adults in this study were living alone ( $n=8$ , 40%) compared with younger adults ( $n=3$ , 6%). Research has suggested that living alone may structurally result in a certain amount of social isolation and impede the development of close social relationships (Hughes and Gove, 1981). For adults with ASD who may have limitations in social skills and communication, living alone could compound their diminished social integration. However, it has also been shown that older people are generally less socially integrated, and as such the higher need for social relationships of older participants in this study may be associated with normative ageing. The difficulties and need for support in the domain of social relationships for adults with ASD is an area that merits further research, and one that must be carefully contemplated in future support planning.

Moreover, in the domain of *communication* 60% ( $n=12$ ) of the older adults with ASD in this study stated they had difficulty either understanding what other people say to them or making themselves understood by others, compared with only 35% ( $n=19$ ) of younger adults. *Inappropriate behaviour* was reported to be a problem for 75% ( $n=15$ ) of the older participants

in this study; a significantly greater need ( $X^2=13.8$ ,  $p<.001$ ) than reported by younger participants ( $n=13$ , 24%). Inappropriate behaviour may be reduced or avoided with the right type and amount of support provided. Behavioural difficulties would need to be considered in future support planning to ensure personalised needs are met.

To conclude this section, participating adults with ASD reported high levels of need across the 25 domains of the CANDID. An exploration of individual domains detailed social, interpersonal, communication and mental health areas to be of particularly high need. Additionally money budgeting and welfare benefits, exploitation and inappropriate behaviours were also key areas of needs in the sample. Comparative analysis of need by age underscored that the older age group reported greater needs across most domains compared with the younger age group. Specifically, the high needs of participants in the areas of mental health, welfare benefits, social relationships, inappropriate behaviour, exploitation risk, communication and money budgeting must be met to ensure their health, safety and wellbeing. However, the low statistical power recognised by the small sample size within the two age groups in this study results in a large standard of error and limits the reliability of the statistical significance reported in these findings. It is possible that these findings are overestimates of effect size due to the small number of participants and the sampling method. The potential of bias in the selection of the sample makes it unrepresentative of the population of adults with ASD and further diminishes the generalisability of these statistical findings. As such these findings are only exploratory, but may be a sound reason to repeat the study to validate the findings of age group differences among adults with ASD. An awareness and understanding of how current needs are being met will indicate areas that may require specific planning to meet the needs of adults with ASD in the future. This is the focus of the next section.

#### **How and by whom are needs being met?**

For each domain in the CANDID where participants identified a support need, they were asked how much help they received from family or friends (informal) and local services (formal) towards meeting the need. Participants could report multiple sources including family, services or both as meeting each need. This section focuses on those participants who identified having needs, and examines the extent to which these needs were met by informal

and formal support. The amount of informal and formal support that is provided is discussed first followed, as before, by a comparative analysis by age group. Findings show regardless of age, the needs of adults with ASD in this sample are primarily being met through informal family support. This may have considerable implications for future support as they and family members age.

Out of a possible 25 domains in the CANDID the average number of domains in which support was provided to participants by family and friends (informal) was 5.8 (sd. 3.9) and by formal support was 2.4 (sd. 2.6). Thus, participants reported higher levels of informal support by family and friends than from formal support in meeting the identified needs. The distribution of help received from informal and formal sources reported by adults within each of the CANDID domains is shown in Figure 6.3. The percentage of support received from family and friends (informal) is represented by the darker coloured column and the percentage of support received from formal services is in the lighter coloured column. It can be seen that within the majority of domains, the level of informal support provided by family and friends towards meeting the needs of the adults with ASD was higher than that received through formal services. With the exception of the medical domains of physical health, eyesight and hearing, help received is predominantly informal support.

Additionally, Figure 6.3 illustrates the domains in which the highest levels of informal and formal support are provided. These include: *other mental health problems* (informal 48%, formal 29%), *social relationships* (informal 43%, formal 20%) and *welfare benefits* (informal 40%, formal 13%). It is surprising that respondents report receiving higher levels of informal support than formal support in the domains of mental health and welfare; this raises concern for future support when families may no longer be able to continue providing support. Moreover, it raises questions about how family are providing support in these domains and why not formal services. In the domain of social relationships, respondents report more than twice the level of informal support than formal support receipt. In the qualitative interviews, participants and their family members expressed inadequacies in social engagement and opportunities for adults with ASD, with social relationships often reduced to only those with family members. Limited friendships and social relationships in adults with ASD have been shown in previous research (Orsmond et al., 2004). In a follow-up study of peer relationships

and social activities among individuals with autism, Howlin, and colleagues (2000) found almost half of participants reported having no friends and a third had acquaintances with whom they interacted with in arranged social groups, but not outside of the group setting. Moreover, research has demonstrated that family play a central role in the initiation and direction of social activities for adults with ASD (Orsmond et al., 2004). With family currently providing high levels of support in the area of social relationships, who will provide this assistance in the future if or when family is unable to continue in this capacity?

In the area of *money budgeting*, a high level of informal support (45%) was also reported in contrast to the level of formal support (5%). Limited abilities to manage money and pay bills may pose challenges in achieving independent living and place adults with ASD at risk of being vulnerable or exploited. Some participating adults with ASD expressed having experienced financial problems as a result of narrow understanding of money, over spending and credit misuse. Family strategies to support their family member with autism in the area of money budgeting included: controlling spending money amounts, managing bill paying and establishing financial trusts for their future.

Additionally, family provided the majority of support for participants at *risk of being exploited* (informal 35%, formal 5%) and with *inappropriate behaviour* (informal 33%, formal 7%). Exploitation included primarily monetary and interpersonal relationships realms. A number of adults with ASD had experienced financial abuse both in person and over the internet. With difficulty understanding friendships some participants recounted being easily influenced by others.

Participating adults, who reported a need in the domain of *inappropriate behaviour*, expressed mostly insistence on sameness, restricted interests, and high levels of sensory sensitivities. People with ASD find comfort in predictability and consistency (Sterling-Turner and Jordan, 2007). Accommodating distinct behaviour patterns, needs and minimizing change could be factored into future support planning.

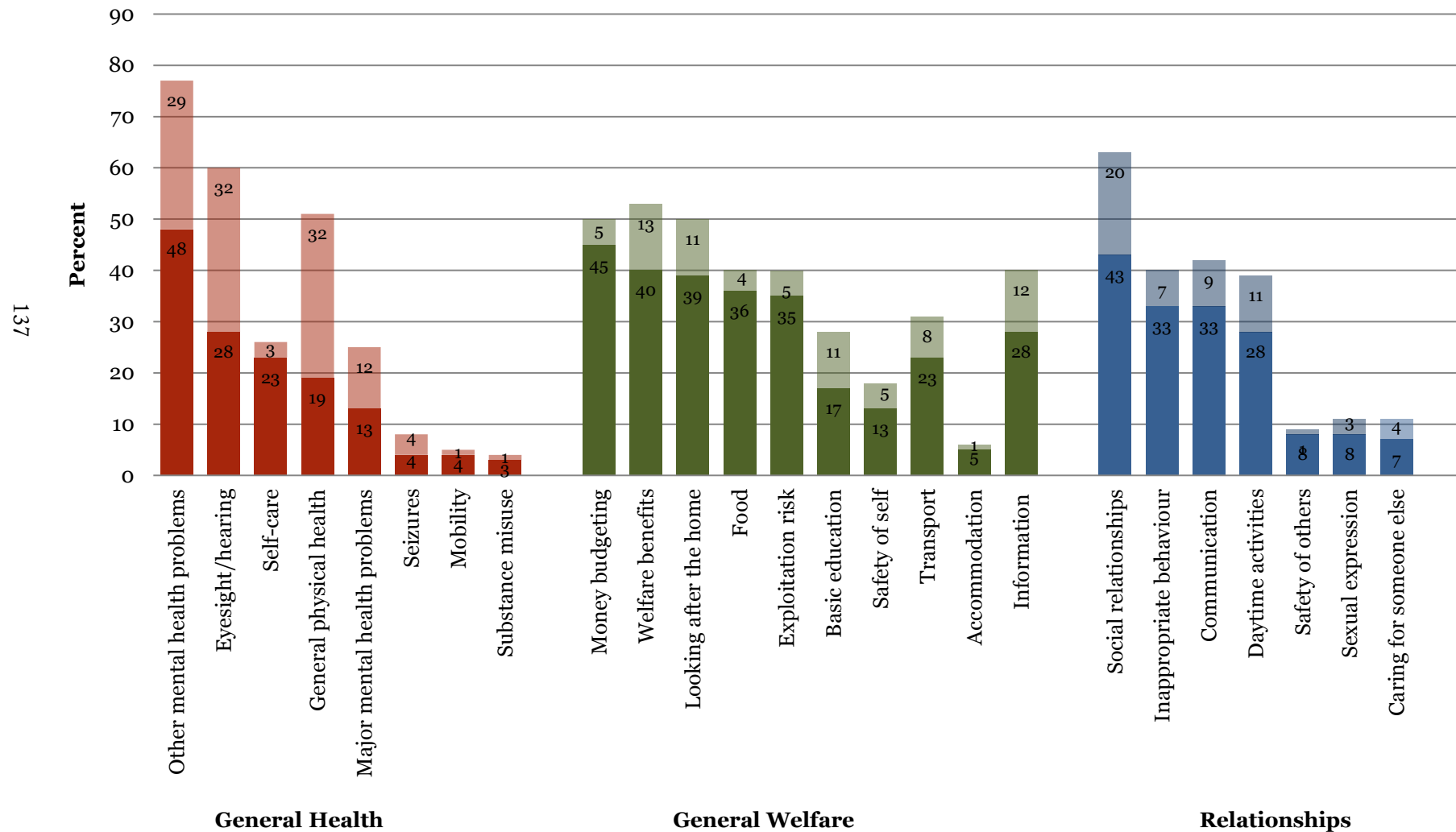
Older participants report receiving significantly higher levels of informal support from family and friends ( $M=8.6$ ,  $SD=3.3$ ) than younger participants ( $M=3.2$ ,  $SD=2.6$ ),  $t=-4.1$ ,  $p<.001$ .



This corresponds with greater reported needs among the older participants as previously shown in Table 6.7. However, the amount of formal support provided is not significantly different between the age groups. Thus family are primarily trying to meet the high needs of older adults with ASD. Furthermore older participants are more likely to lose parental support before younger participants. It may be of greater urgency that alternative support must be planned to meet these high levels of need.

In summary, findings reported in this section are consistent with prior research (Hare et al., 2004, Povey et al., 2011), emphasising that family and friends provide the majority of support to meet the needs of adults with ASD. The heightened extent to which informal support is being provided, primarily by family to older participants, may necessitate future support plans for post-parental support. Additionally, the domains in which some of the highest family support is being provided underscores how vulnerable the participants are likely to be without this support.

Figure 6.4 Distribution of support received from informal and formal services within each domain



The darker coloured columns represent informal support and the lighter coloured columns formal support receive

## What are the unmet needs of adults with ASD?

Prior to identifying the service use of adults with ASD, unmet needs are explored. Not all domain needs for participating adults with ASD were met. As discussed in Chapter 4, previous research has identified high levels of unmet needs for support and services for adults with ASD (Cadman et al., 2012). Similarly high unmet needs were reported in the current sample and are described and illustrated in this section. Participants report highest unmet needs in the domains of *interpersonal relationships*, *welfare benefits*, *daytime activities* and *mental health care*. Moreover, comparatively, older participants report significantly higher unmet needs in these domains than their younger counterparts.

### Unmet needs of total sample

The total sample mean for unmet domains of need was 2.7 (sd. 3.0) with a range of 0 to 17. An unmet need was reported in 23 out of 25 possible domains. In only two areas were no unmet needs reported: caring for someone else and substance misuse. Table 6.5 shows the number of unmet needs for the total sample in descending order for each domain. The number of participants reporting an unmet need in each domain is also shown by age group, and significant differences by age are displayed. The domain with the greatest unmet need reported by 30 (41%) participants was *social relationships*. Ten or more people had unmet needs in ten domains, including: *welfare benefits*, *daytime activities*, *communication*, *other mental health problems*, *money budgeting*, *information*, *inappropriate behaviour*, *exploitation*, and *basic education*. Unmet needs in one or more of these areas could position the individual at risk of vulnerability or isolation. Moreover, the high number of adults with ASD with unmet needs may emphasise essential support service gaps of availability or accessibility. Additionally, areas of heightened concern for the wellbeing of the individual include unmet needs in *major mental health problems* and *safety of self*, expressed respectively by six and five people. Furthermore two people stated their need with seizures remains unmet. These are worrisome claims that may jeopardise health and security. The next section explores differences and similarities in unmet needs by age group.

Table 6.5 Domains of unmet support in descending order by total sample

Domain	Total sample (n)	Age group 18-29 (n)	Age Group 30+ (n)	Chi-square Significance (p)
Social relationships	30	16	14	$X^2=10.5, p=.015$
Welfare benefits	18	12	6	$X^2=8.5, p=.037$
Communication	17	10	7	
Daytime activities	17	9	8	
Other mental health problems	16	7	9	$X^2=20.4, p<.001$
Money budgeting	15	11	4	
Information	15	11	4	$X^2=10.5, p=.015$
Exploitation risk	11	5	6	$X^2=5.7, p=.057$
Inappropriate behaviour	11	7	4	$X^2=18.1, p<.001$
Basic education	10	7	3	
Sexual expression	8	2	6	$X^2=20.6, p<.001$
Safety of self	6	2	4	$X^2=10.3, p=.006$
Major mental health problems	6	4	2	
General physical health	6	4	2	
Safety of others	5	5	0	
Eyesight/hearing	3	1	2	$X^2=11.0, p=.027$
Food	3	0	3	$X^2=13.0, p=.002$
Looking after the home	2	0	2	
Accommodation	2	0	2	$X^2=11.4, p=.003$
Seizures	2	2	0	
Self-care	1	0	1	
Mobility	1	0	1	
Transport	1	0	1	
Caring for someone else	0	0	0	
Substance misuse	0	0	0	

### Unmet needs by age group

Given the small sample size, Figure 6.4 shows the number of participants with unmet needs by domain and age group (rather than percentages). It illustrates that older adults with ASD reported slightly more areas of unmet needs (in 21 domains compared with 17 domains respectively) than younger adults. In six areas, only older participants expressed an unmet need: *self-care, mobility, looking after the home, accommodation, food, and transport*. Unmet needs in these areas may be age-related, and may compromise the health and welfare of the older autistic adult. In two areas, only younger participants stated having an unmet need: *seizures and safety of others*. These are two worrisome areas to have an unmet need both for the safety and wellbeing of the adult with ASD and for others. No participants reported an unmet need in the domains of *substance misuse* or *caring for someone else*. In 15 domains, unmet needs were reported by both age groups. The younger age group had higher unmet needs in nine and the older age group in six of these domains. The categories of general health, welfare and relationships are used to describe and compare domains of unmet needs by age group.

#### *Category 1: General Health*

*Other mental health problems* was a domain of unmet need for approximately a fifth of the sample. It was significantly higher ( $X^2=20.4, p<.001$ ), with an unmet need reported by almost half of older age (9 out of 20) compared to younger age (7 out of 54) group participants. Mental ill-health in ASD has been shown in previous research to be associated with negative long term outcomes in adulthood (Billstedt et al., 2005). Addressing the unmet needs of mental health problem in adults with ASD is an urgent issue. However, self-reported mental health problems reported by participants may be unrecognised or unknown to mental health authorities, which could also account for limited and unmet support in this domain. In addition, various identified unmet needs may be inter-related and have compounding negative effects on mental health. Previous research suggests that social skills training for adults with ASD could increase employability and self-esteem and decrease levels of depression and anxiety (Griffith et al., 2012). Undoubtedly, reported unmet needs in the domain of *other mental health problems* indicated cause for concern for the immediate and long-term wellbeing of adults with ASD.

### *Category 2: General Welfare*

Although informal and formal support provision was high in the domain of *welfare benefits*, almost a quarter of the sample had an unmet need in this area. Additionally 6 out of 20 older adults reported an unmet need in *welfare benefits* while comparatively fewer younger adults (12 out of 54) stated this as an unmet need. Further investigation is needed to ascertain why welfare needs remain unmet and how, if at all, it can be corrected. This may be an area of particular concern for future support if adults with ASD lose welfare support provided by their family.

### *Category 3: Relationships*

Sixteen younger autistic adults and fourteen older ones reported an unmet need in the domain of *social relationships*. As discussed in Chapter 3, functional impairments in social cognition is a core symptom categorising autism, yet for a large number of participants support in this area remains unmet. A 2009 UK government report, *Supporting People with Autism Through Adulthood*, recognises limited social opportunities and recommends the development of social clubs and skills training programs in building relationships with friends, classmates, partners and work colleagues for adults with ASD (National Audit Office, 2009). Thirty-nine participants reporting a need in this domain and 30 of them stating it remains an unmet need, plainly demonstrates a lack of social support in this area. Limited community opportunities and provision of social support for adults with ASD was voiced by many participants. Many also expressed limited social interactions outside of family relationships; while for some this was satisfactory, others expressed a desire for more friends and social opportunities.

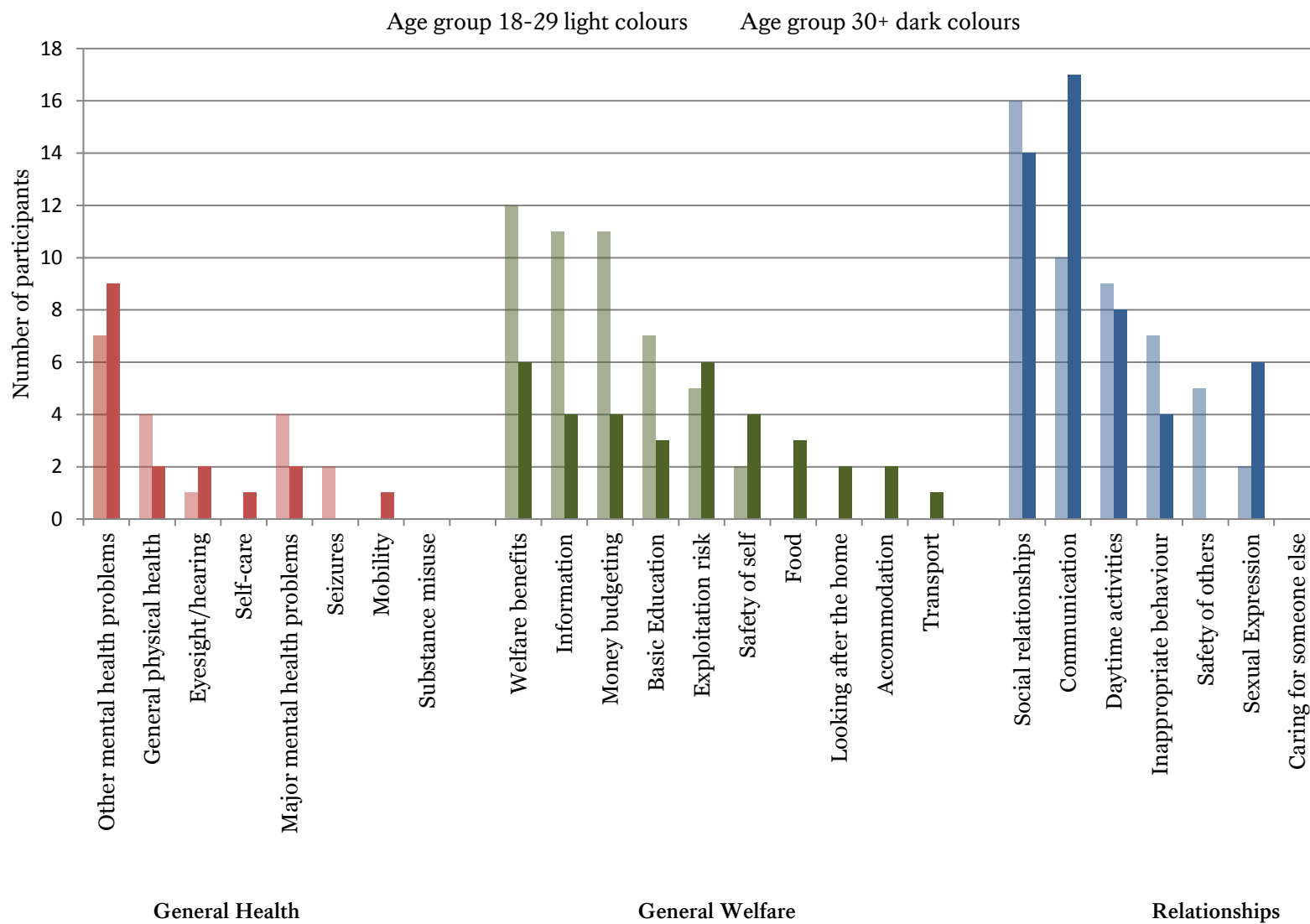
Difficulty with regular, appropriate *daytime activities* was also a high unmet need for almost a quarter of the sample (n=17, 23%). Nine people in the younger and eight in the older group reported an unmet need in this area. Limited social relationships and high unemployment rates among participants may factor into need in this domain. Other research has substantiated unmet needs in these areas recognising limited employment, day and community resources to support the needs of adults with ASD (Gerhardt and Lainer, 2011).

*Communication* was an area of unmet need for ten younger and seven older autistic adults. Difficulty understanding or being understood can place an adult with ASD at risk of harm.

Further investigation is needed to explore specifically what communication needs remain unmet and how to ensure adults with ASD experiencing these difficulties are supported.

In conclusion, unmet needs reported by participants serve to magnify their high level of needs and risks of vulnerability. Furthermore, the reported high level of needs and unmet needs by participants, with most being met primarily by family, emphasises the necessity of preparations and planning to ensure needs are met when family support provision may be diminished. Additionally the multiple unmet needs reported by participating adults with ASD raise concerns for their current and future wellbeing and security. The final section in this chapter addresses the health service use of participants.

Figure 6.5 Number of participants with unmet needs by domain and age group





## What health services do adults with ASD use?

This section explores the health service use of participants using a modified version of the Client Service Receipt Inventory (CSRI). The CSRI (described in greater detail in Chapter 5) includes hospital and community services across a wide range of physical, psychological and alternative health areas, as well as the frequency of their use. As part of the face-to-face meeting in Stage One participants were asked if they had used any health services in the last 3 months that were listed on the CSRI and if yes, how many times. In order to examine health service use in this sample descriptive statistics were used to describe the distribution of participants who reported service use, and frequency of use, in this timeframe. Additionally comparative analysis is used to investigate age differences in health service use in the sample.

Out of the 74 participants only two reported having been in hospital within the last three months prior to the interview; each admission was only one day and both were for reasons unrelated to autism (knee surgery and colonoscopy). In regards to outpatient hospital clinic services, 28 (39%) participants stated they had attended these and all primarily for reasons unrelated to autism. The health service used by the greatest number of adults with ASD (n=43, 57%) and in the greatest quantity (99 times) was General Practitioner (GP) visits primarily for reasons other than autism.

Table 6.6 shows mental health service use, with the number of participants, and total number of visits to psychiatric professional services, as reported by participants. Psychiatric professional services were used to a greater extent than other community services including, social worker and occupational therapist. Although a high need in *other mental health problems* was identified in the sample, less than half of participants (n=33, 45%) had been seen by psychiatric services within the last three months. This corresponds to the high levels of unmet need in this domain reported by participants, and is consistent with previous research in the 2014 Adult Psychiatric Morbidity Survey that reported low levels of treatment or services for mental or emotional problems among adults with ASD (Brugha et al., 2009). Additionally the NAS survey, *I Exist: the message from adults with ASD in England*, stated that approximately one in three adults with ASD experienced severe mental health difficulties as a result of lack of support (Rosenblatt, 2008).

Participating adults with ASD reported high levels of self-support service use with *self-help/support group* used by 18 (24%) at a frequency total of 76 times in the last three months. In addition, *websites/helplines* were used by 23 (30%) participants, who collectively accessed such services 387 times within the last three months.

**Table 6.6 Mental health service use**

Professional Service	Number of participants	Frequency of service use in the last 3 months
Psychiatrist	20	26
Psychiatric Nurse	2	7
Psychologist	11	37
Social worker	12	29
Occupational Therapist	3	3

Comparative analysis between the two age groups in the frequency of recent use of hospital outpatient services, GP visits and other community services found a significant difference in the number of GP visits. Older participants reported more visits to a GP ( $M=3.3$ ,  $SD=3.5$ ) than did younger participants ( $M=1.1$ ,  $SD=1.5$ ),  $t(-2.8)$ ,  $p=.011$  within the last 3 months. This corresponds with the higher reported needs in this age group.

In summary, there does not appear to be a high rate of health service use specifically related to ASD in this sample. Additionally, although no control group was used in the current study findings suggest participants with ASD did not access health or community services disproportionately, aligned with reports from the 2014 Adult Psychiatric Morbidity Survey. Moreover, there is no significant difference in overall service use by age. Most health related services accessed within the last three months by participants were unrelated to core features of ASD. However, the findings also draw attention to the high use of GP services by adults with ASD.

## **Chapter summary**

This chapter highlighted the high levels of needs, unmet needs and service use in a sample of adults with ASD. Findings not only reinforce previous studies, but provide the additional insight that suggests there may be an association between age and the level of support needs and service use among adults with ASD. Older aged participants (30+) had greater levels of met needs, and unmet needs and the number of GP visits in comparison with the younger age participants (18-29). However, needs are not static and can vary overtime. Based on current reported needs and support provision, it appears likely that future areas of need and support for adults with ASD could be anticipated and planned for. How prepared families and formal services are to assume responsibility to meet these needs in the future will be addressed in greater detail in subsequent analysis chapters.

## **Chapter 7: General Health: The implications of a diagnosis of ASD and persistent mental illness for adults with ASD**

The qualitative data adds depth and insight of experiences, family roles, relationships and changes overtime through expanded perspectives of adults with ASD, their parents, siblings and partners. Incorporating timeframes including past, present and future in order to provide a greater whole-person, whole-family, whole-community understanding. Qualitative interviews address the research objective to explore family relationships, concerns, preferences, and future expectations of support for the family member with ASD. The strength of the qualitative findings lies in adding detail and knowledge of the lived experience, current and future desires, and concerns from different family perspectives. It paints a broader picture of the experiences of adults with ASD growing up, of parents raising them and what being a parent, sibling or partner involves. Additionally, the qualitative research examines how and why individuals interact within the social context. Combining the two methods not only provides a more comprehensive and holistic understanding of need and support for adults with ASD across the life course, but also enables comparisons and triangulation of information adding strength and validity to the findings. Together the quantitative and qualitative findings of this research extend the knowledge and understanding of the support needs of adults with ASD and their family members. Additionally, it points the way for areas of future research, advocacy, and actions to ensure the future wellbeing of adults with ASD.

The findings from the quantitative questionnaires in the first stage of this study suggest a relationship between age and three broad areas of need: general health, social relationships, and general welfare. Moreover, discrepancies in levels of need and support provided that were reported between the two age groups may suggest an association with past experiences in a socio-historical context and current support needs of adults with ASD that align with the life course perspective. However, quantitative findings provide only a snap shot of the current reported needs of adults with ASD. Findings from the qualitative interviews in Stage Two of this study exploring the needs of adults with ASD in a broader context, and from multiple family perspectives, are described in the next three chapters. This first qualitative chapter is to explore the perceptions and experiences of participants in the first area of need: general health, using interview data from different family members. Patterns of experience and

perspectives between and within the two age groups are investigated to add depth and detail to the quantitative findings. Two central themes emerged through text analysis: diagnosis of ASD and persistent mental illness. These themes address the research questions: (i) what are the needs of adults with ASD, emphasising the requirement for a diagnosis and services to treat the high prevalence rate of ongoing mental illness; and (iii) what are the unmet needs of adults with ASD, by underscoring that improvements have been made in the diagnostic process, while there remain unmet needs for mental health services and support for adult with ASD. The chapter begins by discussing the first of these, diagnosis, focusing on the lived realities and meanings ascribed to experiences and situations associated with the acquisition of an ASD diagnosis. Subsequently, the insights and impact of living with persistent mental illness are presented. Discussion is embedded in each section, and the chapter concludes with a summary of key findings.

## **Sample**

These findings are based on face to face interviews with 49 family members (21 adults with ASD, 16 parents, 4 partners and 8 siblings) representing 21 families. Individual, semi-structured interviews explored life experiences of being or parenting an adult with ASD, as well as experiences of partners and siblings of adults with ASD. Table 7.1 shows participant pseudonyms, age at interview, age at diagnosis, marital status, living arrangement and family relationship.

### **Adults with ASD**

Twenty-one adults diagnosed with ASD participated in this stage of the study. Ten were recruited from the younger age group (18-29 years) with a mean age of 24 years. All were residing with their parents and the majority were unemployed and not in education. Eleven adults with ASD in the older age group (30+ years) were interviewed, with a mean age of 48 years. Three were living with their parent, four lived alone and four lived with a partner. None of the older adults with ASD were in education, three were employed (two part-time and one full-time) and two volunteered on a weekly base.

### **Parents of adults with ASD**

Sixteen parents were interviewed individually, 10 were parents to younger adults with ASD and 6 to older adults. The mean age of the participating parents was 64 years. Nine parents were 60 years of age and older, six of whom were over the age of 70 years. Moreover, six of the nine parents over the age of 60 still had their adult child with ASD living with them. All but one parent interviewed were mothers. Eight parents were married and living with their spouse, five were divorced and three widowed.

### **Siblings and partners of adults with ASD**

Eight siblings participated, five of adults in the 18 to 29 age group and three whose sibling was 30 years of age or older. Four siblings were older than their brother or sister with ASD and four were younger. Five siblings were male and three female. Four siblings were single, never married; three were married and one in a cohabitating partnership. Four partners, all with an older adult with ASD (30+), took part in interviews; two were married and two cohabiting. In all participating partners it was the male partner who had ASD. The length of time of the couple relationships ranged from 3 to 20 years with a mean of 11 years.

Table 7.1 Participant Pseudonyms

Adult with ASD (Age group 18-29 years)					Parent			Sibling			Partner	
Pseudonym	Age (years)	Age at diagnosis (years)	Marital Status	Living arrangement	Pseudonym	Age	Marital Status	Pseudonym	Age	Marital Status	Pseudonym	Age
Albert	25	4	Single	Lives with parent	Ann	62	Married					
Bruce	22	3	Single	Lives with parent	Betty	56	Married	Brian	21	Single		
Claire	19	11	Single	Lives with parent	Charlotte	51	Divorced					
Derek	29	27	Single	Lives with parent	Diana	68	Married	Debbie	32	Cohabiting		
Elliot	23	15	Single	Lives with parent	Emma	55	Married	Eric	29	Single		
Frank	27	3	Single	Lives with parent	Fiona	66	Married					
George	24	8	Single	Lives with parent	Grace	44	Divorced	Gregory	22	Single		
Harry	23	5	Single	Lives with parent	Helen	51	Married					
Ian	23	10	Single	Lives with parent	Iris	55	Divorced	Irving	23	Single		
James	24	17	Single	Lives with parent	Jane	55	Married					

Adult with ASD (Age group 30+)					Parent			Sibling			Partner	
Pseudonym	Age (years)	Age at diagnosis (years)	Marital Status	Living arrangement	Pseudonym	Age	Marital Status	Pseudonym	Age	Marital Status	Pseudonym	Age
Kate	40	37	Single	Lives with parent	Kay	71	Divorced					
Liam	56	5	Single	Lives with parent	Lucy	91	Widowed	Laura	62	Married		
Mark	41	37	Single	Lives with parent	Mary	67	Married	Matthew	38	Married		
Neal	47	44	Single	Lives alone	Norma	76	Widowed	Nancy	54	Married		
Owen	65	46	Single	Lives alone	Olivia	91	Widowed					
Paul	38	30	Single	Lives alone	Peter	70	Divorced					
Robert	51	48	Cohabit	Lives with partner							Rebecca	49
Stephen	45	39	Cohabit	Lives with partner							Sarah	49
Thomas	47	44	Married	Lives with partner							Tracy	32
Victor	53	49	Married	Lives with partner							Virginia	55
William	44	43	Single	Lives alone								



## Overview of chapter findings

No interview questions explicitly asked about diagnosis, but the process of searching for answers and receiving a diagnosis of autism dominated the conversations, signifying its salience as a theme in this research. Parents of adults with ASD from the two age groups were similar with regards to recognising behavioural and developmental differences in their child, and seeking medical expertise to explain them. However, they differed in their experiences with medical personnel and social support. It was here that the life course theory principle of the interplay between human lives and historical time may offer possible explanations for these differences. In the interviews, the parents of older and younger adults with ASD described their experiences in acquiring a diagnosis for their child. Two concepts related to the theme of diagnosis were developed from analysis of the interviews that distinguished the experiences of participants of the two age groups: unknown and known. The concept of unknown refers to being undiagnosed with autism, and a general lack of awareness and understanding of the condition, particularly as the individual with ASD was growing up. The time frame of the experience of not knowing varied among participants, often extending for decades among older adults with ASD. The impact of not having a diagnosis of autism affected all family members. The concept of known indicates living with a diagnosis of autism, knowing more or less what to expect and what to do. These two concepts represent the essence of the struggles, frustrations and meaning of receiving a diagnosis of autism for family members. Moreover, they reflect the different social and historical contexts in which the two age groups of adults with ASD grew up. As such the experience of known and unknown is presented from the perspectives of parents, adults with ASD, siblings and society at large. Analysis revealed historical time, severity of presenting symptoms, and the existence of comorbidities, influenced the outcomes associated with receiving a diagnosis, and access to support services. Moreover, findings highlight an ongoing societal 'unknown' of the support needs of adults with ASD through limited awareness and availability of support services.

A second theme, mental illness, was prominent as many adults with ASD expressed current and persistent mental illness and its debilitating effects across their life course. Three categories encapsulated accounts of mental illness: a) looking back: anxiety and stress being a constant presence in their lives until this point, b) the overwhelming functional limitations of mental illness, and c) looking ahead: vulnerabilities and concerns. Pervasive mental illness

compounded the complexity of ASD and imposed further limitations. Additionally, family members worried about the future mental wellbeing of adults with ASD when emotional and practical family support might be diminished or absent. The transition process for adults with ASD out of parental care to independent living or to other informal and formal support provision was a constant concern for all. Many adults with ASD had not made normative adulthood transitions, continuing to reside with their parents, never having been employed or had a long-term relationship. For some, their adult lives could be described as liminal.

Liminality was introduced by ethnographers Van Gennep and Turner as a descriptive concept of the transitional stage in rites of passage in the indigenous societies they observed (Turner, 1987). Liminality represents the temporary phase between stages, such as adolescence and adulthood. Intangible and tangible boundaries must be crossed before the individual can enter a new stage of acceptance and integration into the social order of the society (Van Gennep, 2011). Liminality embodies a suspended state, being on the threshold, not yet having made the complete transformation. It is described as being in limbo, betwixt and between the social order and acceptance of the society (Turner, 1969, Turner, 1987). The concept of liminality has been applied in disability studies with regards to the status of individuals with physical disabilities in society (Murphy et al., 1988, Willett and Deegan, 2001), and in medical sociology related to people living with a life-threatening illness (Bruce et al., 2014, Little et al., 1998). Liminality may define and describe the ambiguous lived experiences of adults with ASD and their family members. While liminality is not a developed theory, it provides a useful concept for specific aspects of life transitions for adults with ASD. Unidentified and unmet support needs may contribute to the liminal status of adults with ASD in the contemporary societal context.

The centrality of diagnosis and mental illness are key findings in this research that explored the support needs of adults with ASD. A diagnosis is often required for the provision of services and formal support. Advice and guidance following a diagnosis may help family members and adults with ASD know how to proceed: to develop relevant strategies, facilitate access to support services, and plan for the future. In addition, this study found how a diagnosis of autism and the persistence of mental illness impacts family roles and relationships, which was underscored by the experiences described in interviews. The role family members

provide can be particularly challenging as they may be caught between meeting the needs of their family member and that of advocating and navigating a system that is both difficult to understand and has limited resources. Understanding the experiences of diagnosis and mental illness of adults with ASD and their family members may help inform and improve services and formal support provision to meet their complex needs.

### **A diagnosis of autism**

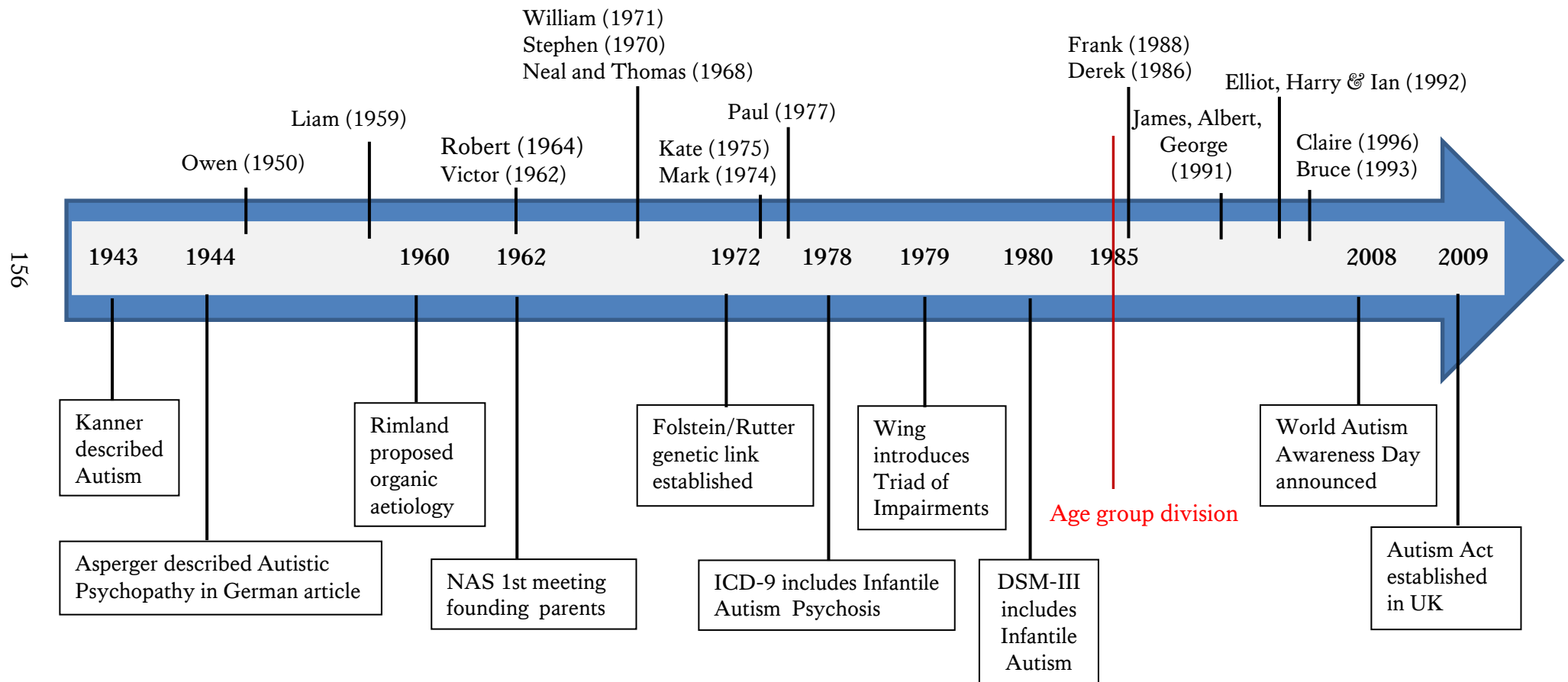
Whether or not parents received a diagnosis and explanation for the differences they observed with their child in early childhood distinguished the recounted experiences of parenting a child with ASD between the two age groups. Most adults with ASD from the older age group did not receive a diagnosis in childhood, and their parents did not know what precipitated the differences they recognised or how to proceed in parenting their child. Most younger aged adults with ASD received their diagnosis in childhood or adolescence, and parents received and had greater access to autism information and support. Although having a diagnosis and knowing the reasons for certain behaviours and limitations did not necessarily minimise difficulties for parents, it did enable fuller awareness and understanding of their child. Additionally, older adults with ASD expressed being self-aware of differences in childhood and described the distress of not knowing why. Knowing or not knowing a reason for perceived differences impacted all family members, influenced parenting practice and community engagement.

For most of the adults with ASD and their family members, their story does not begin with the diagnosis, but starts many years before. The past experiences of recognising a difference, identifying a problem, and seeking professional advice and expertise elicited descriptions, comparisons and remembrances of anguish and frustration prior to getting a formal diagnosis. Parents universally used descriptive words, such as ‘difficult’, ‘challenging’, ‘a battle’, and ‘a struggle’ to express the process of raising a child with ASD to adulthood. All parents collectively recalled feelings of exhaustion, being overwhelmed, stress and frustration in parenting their child. Yet, it soon became apparent in analysing the texts, that although the parents were expressing the difficulties they experienced raising their adult child with ASD, it was more than just the developmental and behavioural dimensions that distinguished the problem. What became clear was a distinction between having and not having an explanation

for the perceived differences. Specifically, a large part of what defined the difficulties the parents were expressing was knowing or not knowing what they were dealing with. A diagnosis of ASD offered understanding and provided direction; a void in both was the course without a diagnosis. Moreover, this impacted the lived experience and was relative to historical context.

The different experiences of parents, adults with ASD and their siblings from the two age groups are presented in the following sections. The concept of the unknown is introduced first. It represents primarily the experiences of participants from the older age group (30+ years) and the social historical environment when these adults with ASD were children. The concept of known is presented second aligned with chronological time. It includes the advantages younger aged participants experienced having a diagnosis in childhood and the changes in autism knowledge, awareness and support in the historical context in which they grew up. Figure 7.1 shows the historical time line of ASD with the year in which participating adults with ASD were born mapped onto it. Additionally, the year that divides the two age groups is identified to distinguish the socio-historical context in which they were raised. Moreover, the concept of known also incorporates the personal and practical meaning of receiving a diagnosis of autism in adulthood experienced by older age group participants and their families. In addition to comparative differences between age groups reported in the concepts of unknown and known, a number of within age group differences are presented. The chapter concludes with a summary of the key findings in the theme of diagnosis, highlighting substantial differences between the two age groups of adults with ASD and the relevance of the life course theory.

Figure 7.1 Historical timeline and participant birth year



### **The unknown: implications of no diagnosis of autism in childhood**

The different historical time in which mothers raised their children helps provide context to their experiences of knowing or not knowing a reason for observed differences between their child and others (see Figure 7.7). In the 1950s, 60s and 70s, when the parents of older adults with ASD were raising their child, autism was relatively an unknown, rare entity (D'Astous et al., 2014). Moreover, the diagnostic criteria of autism have changed over time (see chapter 2). In the past, when many older participants with ASD were children, the diagnostic criteria were narrower and required greater severity of symptoms. Some older adults who have recently received a diagnosis of ASD may not have met the more narrow diagnostic criteria when they were children (Bishop et al., 2008). Furthermore, in the past when autism was considered a rare condition, many physicians may have been reluctant to label a child as autistic until symptoms became more obvious (Bishop et al., 2008). Thirty or more years ago, many children with ASD were simply not diagnosed or misdiagnosed (D'Astous et al., 2014). As such, parents received no explanations or answers to what they perceived as problems.

#### *Parents*

Not having an explanation for different behaviours and developmental delays observed in their children was problematic for most older age group parents. They recalled knowing that something was wrong with their child but felt their concerns were dismissed by medical personnel with little explanation or were unable to be labelled. Some were told their child would 'catch up', while others received a diagnosis other than autism, such as intellectual disability and anxiety neurosis. Mary is the mother of 41-year-old Mark, who received a diagnosis of ASD at 37 years of age. Mary recalled Mark being examined at the age of 7 years in 1974 at her insistence that there was something wrong.

'We were told they could not put a label on him so they couldn't help us, so basically go away and get on with life.'

Mary, mother of 41-year-old Mark

Parents reported feeling unheard and unacknowledged by the doctors from whom they sought answers, and were generally unsatisfied and discouraged with their experiences. Yet at the time when these parents sought medical advice to explain behavioural and developmental differences in their children, the trust-based knowledge and authority given to medical practitioners would not have been contested (Evetts, 2006), nor were there

alternative sources of information or support available to parents. Medical authority and its exclusive hold on medical knowledge only began to be questioned and challenged during the 1980s and 1990s (Halpern, 2004). As such these parents went home and got on with life. Parents reported that they received no explanations or answers to what they perceived as problems and no assistance with parenting. Forty-seven-year-old Neal is Norma's fourth child, born in 1968. Comparing his behaviour and development with that of her other children, she recognised clear differences at an early age that worried her. Neal did not receive a diagnosis of ASD until he was 44 years old. Norma explained part of the difficulty in raising Neal was that she had no idea why he was 'so weird to bring up', nor did she have any guidance in how to parent Neal, 'I had to do it differently than my other three'. The challenges of parenting their children without a diagnosis of autism were confusing and isolating. Mothers expressed feeling very alone in parenting their child. Most reported their husbands being 'out working' and perceived that they had been unaided or supported when their child was young.

'I was basically on my own because his father in the growing up years was not around. He was out working. I brought him up more or less on my own and it was very hard work'.

Mary, mother of 41-year-old Mark

The social environment that mothers of older aged adults with ASD reported was that of the 1960s, 70s and 80s. All but one of the mothers did not work outside the home. They explained that parenting advice was not readily available, primarily limited to recommendations of extended family members or friends, and that raising children was largely the mother's responsibility. They described being self-reliant. 'You were on your own', stated 76-year-old Norma; and 91-year-old Lucy described parenting her autistic son as requiring, 'instinct and attitude'. Mothers also reported that extended family members were unsupportive and often added to their difficulties. Lucy, the mother of 56-year-old Liam, born in 1959, recalled how she received no help from her parents or support in raising him.

My father died very early on in my marriage, so he did not know my children and my mother was not helpful. She didn't understand and she just considered him stupid. She was not interested or helpful.

Lucy, mother of 56-year-old Liam

Additionally, Lucy's husband died before Liam was 2 years of age and she parented him and his older sister alone. Lucy and other parents described being resilient, 'mucking through'

and ‘doing the best they could’ with very limited support and information. Not knowing why their children exhibited behavioural and developmental differences, and parenting with limited information or social support compounded the difficulties parents of older adults with ASD experienced. It is now understood that a diagnosis of autism for a child enables parents, as well as others, to understand and support the child better (Abbott et al., 2013). Not knowing what was wrong reportedly added to parents’ stress and made it hard to know what to do. Additionally, without a diagnosis of ASD the children themselves had no understanding of their apparent differences and limitations.

### *Adults with ASD*

Remarkably, only older aged group adults with ASD expressed an awareness of being different to their siblings and peers growing up and not knowing why. Some recollected a time when they specifically recognised being different, while others conveyed remembering comparative differences to others across their life course, particularly in regards to social interactions. Kate, a 40-year-old adult with ASD, expressed remembering when she identified as a child that she was different.

‘I have a clear memory I think when I knew that there was something wrong with me. We had to learn about maths and the teacher set up this travel agency and we had a role and cast in a situation that we had to do in front of the school and I couldn’t remember my lines and we had to adlib and I could not do it. I got the sweats and I was freaking out. They finally understood and pulled me out. I was so stressed and I remember thinking why can’t I do this and I knew then that there was something not quite right with me. It was in primary school, so I was about 8 or 9 and I knew there was something wrong with me, because everyone else could do it and I couldn’t. But because they did not understand they thought I was an odd, moany kid.’

Kate, 40-year-old adult with ASD

Kate’s quote describes not only her feelings but also the social context of when she was in school in the 1980s. She described school as a tortuous experience, a mixture of confusion, humiliation, heightened anxiety and bullying. Her teachers did not identify her symptoms of autism. There were no accommodations for her social limitations or differences in learning style in the mainstream schools she attended. She was eventually diagnosed with dyslexia in secondary school, but her ASD was not identified until she was 37 years of age. Kate received no educational support and reported she endured stress and bullying in school. Growing up Kate expressed experiencing liminality, feeling different, being unaccepted by her peers and having her needs unrecognised by her teachers. She recalled that she ‘never fit in’.



Recollections of the past by other older aged adults with ASD suggested they also recognised a difference in comparison to others. William, a 44-year-old adult (born in 1971), only received a diagnosis of ASD at 43 years of age. He stated that when he was a child his stepmother was always saying, ‘Why can’t you be like everybody else?’ William explained that he followed rules and requests exactly and could not deviate or self-initiate anything. When his stepmother would ask him to do something he would only do explicitly what she asked and did not assume any further actions. For example, if she asked him to take his clean clothes to his room, that would be all he would do. He would not put them away in his closet or drawers. He stated he literally did just what he was asked and nothing more, because ‘it did not cross his mind’. His stepmother compared his behaviours to ‘others’, yet neither he nor his stepmother had an explanation for the dissimilar behaviours. Mark, a 41-year-old adult, remembered comparing his different social, behavioural and learning abilities to his younger brother and wishing he could be more like him.

‘I didn’t understand it and I was very frustrated. He had all the girls, he moved out and he went to uni.’

Mark, 41-year-old adult with ASD

Having no defined reason for these differences was a source of frustration to Mark. His experience is one of liminality; living outside the margins of what he perceived to be ‘normal’. He stated, ‘I always knew something was wrong with me’. Mark did not receive a diagnosis of ASD until the age of 37 years.

For younger aged group adults, having a diagnosis of ASD in childhood or adolescence that identified a root cause of any behavioural or developmental differences provided them with a reason for their differences. Knowing they were autistic at a young age helped to explain self-perceptions of differences they may have felt, and as such it was not something they discussed in the interviews. Their parents, themselves and other family members had long been living with a diagnosis of ASD, knowing what to expect and what to do. Moreover, their academic environment classified their differences and provided additional support to meet their needs. The older aged adults had no explanation for their self-perceived differences throughout their childhood and most attended mainstream schools without specific academic support.

### *Siblings of adults with ASD*

Only three siblings, two sisters and one brother, of older adults with ASD were interviewed. They all expressed knowing their sibling with autism was different when they were children despite the lack of a diagnosis. Matthew is the younger brother of 41-year-old Mark, an adult with ASD. He described the frustration and limited help Mark experienced growing up without a diagnosis of ASD. Mark did not receive a diagnosis of ASD until he was 37 years old.

‘I’d hate to have been him. Growing up has been horrendous for him in limbo and it was terrible. He didn’t have a proper label or the proper support.’

Matthew, brother of 41-year-old Mark

Matthew implied a lack of a diagnosis placed Mark in an indeterminate state. Family members and people in the community did not know why he behaved the way he did, nor how best to support him. Not knowing why Mark was different, Matthew explained he was considered a ‘spaz’ by his peers and that he did not have a ‘natural badge’ that identified and explained his limitations. Matthew is referring to the invisibility of autism compared with other disorders such as Down syndrome. Mark has no physical or observable characteristics that identify him as having limitations and needing support. Moreover, the social environment at the time was not tolerant or understanding of his differences. There was not a general knowledge or awareness of autism in the community or in the educational system when Mark was a child.

‘He is normal enough to be at a disadvantage, for people not to have the patience, not to be tolerant, and not to assume. They do not have the culture of empathy that we, as a family have grown to’.

Matthew, brother of 41-year-old Mark

Here Matthew is not only referring to the environment of their youth, but also he implied that today a general understanding and awareness of ASD in adulthood is still missing. An increased awareness and knowledge of ASD among the general public does not necessarily infer greater accommodation and kinder interaction for adults with ASD. He feels his brother suffered and continues to suffer as a result. Thus although the diagnosis of ASD provided relief and understanding of the behaviours and limitations Mark displayed, he remains living in an indeterminate state of liminality with his limitations unrecognised within the social context and unsupported by services. Mathew described that Mark ‘looks normal’, he can converse and that he appears more capable than he is, consequently people are unkind and

intolerant of his social limitations. Like many adults with ASD, Mark's limitations are transparent. Placed in a liminal situation without a diagnosis or an observable disability, certainties were lost and the child and family lived a life of betwixt and between, never being fully integrated with peers or within the community.

### *Societal context*

The historical social context in which the older aged adults with ASD were raised is important in understanding their and their families' experiences. For some older parents their persistence in seeking answers was met with ignorance and intimidation. Perhaps one of the most difficult and distressing situations mentioned by parents was when they believed that features of autism were misunderstood by professionals and they were considered to be causal to their child's behaviour. Some of the older mothers expressed they were made to feel incompetent as a mother by the people from whom they sought answers. As discussed in Chapter 2, maternal blame for their children's problems was common practice in the mid-20th century (Bettelheim, 1967, Kanner, 1965). Stigmatising blame and incompetence in parenting may have been imposed on mothers of adults with ASD in the older age group, as it was common understanding among professionals in the time period they were raising their children. This was voiced in Norma's experience with the doctor. Norma, aged 76, is the mother of four children; three sons and one daughter. Her youngest, 47-year-old Neal, had only recently been diagnosed with ASD, although she had initially raised concerns with the general practitioner (GP) when he was an infant and repeatedly throughout his childhood and adolescence.

'Before he was 2 [years old] I took him to the doctor and was told I was a very fussy mother who should learn to interact with my child.'

Norma, mother of 47-year-old Neal

The doctor stating she was, 'a fussy mother who should learn to interact with her child', insinuated that the problem was with her parenting skills and not with Neal's behaviour or delayed development. That she 'should learn to interact' with her child is consistent with the Freudian ideology of that time period. Forty-five years ago (in 1970) the notion of poor parenting as the causal factor of autism remained in the forefront for many researchers and physicians. Moreover, inappropriate interpretations of the problems recognised by parents served to delay constructive approaches and interventions to effectively meet the needs of the child with ASD and to provide necessary support, services and resources to the entire family.

Parents of older children alluded to not only feeling unsupported within their families in parenting their child, but also to feeling isolated within their community. When their children were growing up there was little social awareness or support for children with ASD. Liam, age 56 years, was the only adult in the older aged group to receive a diagnosis of ASD in childhood. The severity of Liam's symptoms may have may resulted in his diagnosis in childhood. Lucy, Liam's mother described that when he received a diagnosis in 1963 societal understanding of autism was negligible. People did not understand or make allowances for his behaviour, social or communication limitations. As such, any proffered insight into his condition or requests for accommodations to his needs were ignored or disregarded.

'In the very early stages people here did not know anything about autism and the NAS didn't even exist yet. It was very difficult taking Liam out with his strange behaviour and if he saw something that frightened him he would just scream and scream and you couldn't stop him and he couldn't tell you what was wrong. I would get stares and bad looks and people objected to his autistic behaviour.'

Lucy, mother of 56-year-old Liam

The understanding of autism and the availability of support in the social environment when these older aged group of adults with ASD grew up is a reflection of the interplay between human lives and historical time. Not only did limited medical understanding and narrow diagnostic criteria result in few older children in this study receiving a diagnosis of autism, the availability of information and social support was inadequate for the parents. They had no alternative informational sources; books about autism and parenting a child with autism were negligible and the World Wide Web did not exist. Social advocacy and support groups such as the NAS were just beginning (see Figure 7.7). General public and professional awareness of autism was absent or skewed by the Freudian ideology of the time. Thus, the social-historical environment of the mid-twentieth century contributed to the experiences of seeking a diagnosis for older aged group participants. The status of children with ASD and their families was liminal; they lived on the threshold of society neither recognised nor accepted in the community. They lived and interacted in a different social and historical time than younger aged group families. The experiences of adults with ASD in the younger age group are described next.

### **The known: living with a diagnosis, knowing what to expect and do**

The delineation of the diagnostic criteria for autism has been expanded in the last few decades to include a wider spectrum of problems with communication and social interaction (see Chapter 2). Moreover, medical and general understanding and awareness of autism has likewise increased. This is the social-historical environment in which all younger adults with ASD (18-29 years) were born and raised (see Figure 7.7). Most received a diagnosis and associated support in childhood. As such most of them and their families had been living with the knowledge of ASD since they were children (see Table 7.8). Knowing a reason for the observed behaviours and developmental delays appeared to influence the lived experience of all family members.

#### *Parents*

Accompanying the diagnosis of ASD in childhood or adolescence was knowledge and understanding. Although parents reported that prior to the diagnosis they did not know much about ASD they were able to access information when a diagnosis was given. Emma, 23-year-old Elliot's mother explained that she sought out and read books to inform herself about ASD after Elliot received his diagnosis in adolescence.

'It was at once a massive shock, kind of like discovering someone you thought you knew had something quite significant missing or different and you hadn't a name for it. So it was a big relief because we knew where we were then. The first book I read was the one by Tony Attwood. It was very good and I found it quite helpful. I read anything that comes out on Asperger's.

Emma, mother of 23-year-old Elliot

The diagnosis of ASD formed a base from which parents could advance their understanding. The observed differences and difficulties now had a name and label. Informing themselves about ASD was the next step referred to by parents. They related the availability of and access to information about ASD as being widespread in the early 2000s when Elliot and other the younger aged group adults with ASD were children. The historical social context in which these parents raised their children included informational and support charities, such as the NAS (see Figure 7.7). Charlotte, 19-year-old Claire's mother, described the availability of resources she accessed for information and support.

'There is quite a lot and I make it my business to find out what is going on. I am a member of the NAS and Asperger's Foundation and I am interested in going to any talks that I can go to and through my peers I find out about different resources and things.'

Charlotte's comment acknowledges not only the prevalence of information on ASD but also its common knowledge within her social environment. Her friends and work colleagues are aware of ASD and attuned to informational resources. Moreover, the knowledge that ASD is an organic brain disorder has diminished the stigma of having a child with the condition. Charlotte perceives no blame and candidly communicates and interacts with members in her community to gain information and support in parenting Claire.

Changes in ways of communicating knowledge, the authority of knowledge and access to medical information has vastly expanded in the last few decades. What was previously the domain of expert knowledge of medical practitioners is widely available to the lay public. The World Wide Web, established in the 1990s has resulted in the general public in Western societies being consumers of health information (Cline and Haynes, 2001, Hart et al., 2004). Today, the widespread provision and availability of medical information via the internet, television and books has contributed to dissolving the boundaries between expert and lay knowledge (Hardey, 1999), although it is important to note that the internet also a source of misinformation. Moreover, supportive information, services and groups are offered for parents, adults with ASD, siblings and partners. The vastly expanded availability and accessibility of information and services for parents of children with ASD today is incomparable to the limited information and resources that parents of adults in the older age group experienced when they were raising their child in the 1960s, 1970s and 1980s.

As well as the search for information, the acquisition of a diagnosis induced parents into action. 'When it was picked up that there was an issue, I threw myself into it', stated Helen, 23-year-old Harry's mother. Harry was diagnosed with autism at the age of 5 years, in 1997. Parents described a range of actions including various therapies, techniques and strategies they utilised; for example, speech and language therapy, special diets and volunteering in school. Knowing their child had ASD provided parents with direction in parenting and offered them the ability to advocate for the needs of their children. Grace, 24-year-old George's mother, explained how her life changed when he received a diagnosis of ASD at the

age of 8 years old in 1999. She described how the diagnosis of ASD helped her to understand what she was dealing with and how to proceed.

‘It changed my life. I didn’t scream as much, because I used to shout a lot. And I thought; right, now I know what I am doing, I have somewhere to go, we can do this and life became better.’

Grace, mother of 24-year-old George

Grace explained how receiving a diagnosis for George affected the way she interacted with him and how she instructed others to accommodate his needs. Prior to a diagnosis Grace reported yelling at George in frustration. She was ignorant of the reasons for his behaviours, which included being destructive and aggressive, and was exasperated in her efforts to parent him. Knowing George had ASD altered the way she parented and helped her understand his behavioural difficulties and social limitations. She described developing consistencies in daily routines and allowing him to carry certain comforting things with him all the time to help him cope. ‘Those are his constants within chaos’, she stated. Additionally, she described volunteering throughout his school years to try to ensure his support needs were met. However, parents stated advocating to have their child’s needs met was not an easy process. Grace captures the sentiment expressed by many parents:

‘You feel like you are constantly battling and you can’t relax. You are always at war with somebody.’

Grace, mother of 24-year-old George

Grace explained that she can never relax and ‘just do normal family things’; she said that, ‘she never switches off’. She described fighting to get him support at school, fighting with a psychiatrist to be allowed to sit in on his sessions, and with the public when people tell him he cannot wear his ear phones. The subject of advocating for support needs is addressed in further detail in Chapter 9.

The life course theory principle of the inter-relationship between the social and historical context and individual lives is demonstrated in this section of knowing and living with a diagnosis of ASD. The societal and cultural environment afforded these children a diagnosis, offered their parents knowledge and information about ASD, and to some extent facilitated and supported accommodations of their needs. In the 1990s, the understanding and awareness of ASD was beginning to filter into general knowledge and spread into support services for children. Grace’s reaction and advocacy within the community for her son George following

his diagnosis demonstrates the link between knowledge and support. The social context and understanding of ASD facilitated her explanations and requests within the community. Knowledge of, and support for, children with ASD has significantly expanded within the public and professional communities since 1985. Moreover, this expanded awareness and understanding contributed to the older adults in this study receiving a diagnosis of ASD in adulthood. The knowledge and impact of a diagnosis of ASD in adulthood is described next.

*Receiving a diagnosis of autism in adulthood: the same only different*

For all but one older aged group participant, a diagnosis of ASD was only received in adulthood. As previously stated, nearly all had no diagnosis in childhood and others had been misdiagnosed at an earlier age. However, even in adulthood more often the process of seeking a diagnosis was initiated by parents and not the adults with ASD themselves. Their pathway to diagnosis was often precipitated by a social or mental health crisis. The personal crises described by participants are examples of factors that researchers Matson and Neale (2009) described as “behavioural triggers” that prompt further evaluation or assessment. Mary described her 41-year-old son Mark’s serious financial trouble, his lying and telling stories. Mark had obtained multiple credit cards using own his name as well as his father’s and his brother’s, and had used up all of the credit without ever making monthly payments. She explained he did not seem to understand the consequences of his actions. When confronted about it, he denied doing it. Threatened with legal and financial costs, Mary’s concerns and frustrations reached the point where she told Mark, ‘right I can’t deal with this anymore, we are going to the doctor’. Mark was diagnosed with ASD at the age of 37 years.

The problems of atypical behaviour in adulthood prompted the pursuit of a diagnosis for many of the older aged participants. Two adults with ASD described experiences with the law; one explained being the victim of repeated sexual abuse, and another financial misconduct as the pathway that instigated the process of an ASD diagnosis. Kate is 40 years of age, she received a diagnosis of ASD at the age of 37 years. Kate described her frustrations and efforts to get answers from medical professionals to explain why she had so often experienced being the victim of sexual offences.

‘I got my diagnosis of autism because they finally agreed that getting raped or molested on a regular basis at my age is not quite normal. I also got my diagnosis because I got in trouble with the law, even though I am so law abiding, but I got in trouble because I did not understand. If it wasn’t for that I would never have got it.’



Kate, a 40-year-old adult with ASD

With no visible signs to identify her social limitations, Kate's behavioural patterns were important in the diagnosis of ASD. She had difficulty interpreting social cues and communication. Additionally, for a few participants a diagnosis was prompted as a result of a mental health crisis. Peter is the father of 38-year-old Paul, an adult with ASD. Peter expressed that at the age of 30 years Paul lost his job and became very mentally ill. For Paul, the crisis of mental illness was the behavioural trigger that instigated further assessment. He was diagnosed with ASD that same year. Peter described Paul's mental health as 'stable' at the moment but stated he worries particularly about his mental wellbeing in the future when he is 'no longer around' to help support his son.

Most parents expressed feeling a sense of relief and validation when a diagnosis was finally given. Mary's son Mark only received a diagnosis of ASD at the age of 37 years. She explained that she burst out crying when the physician told them Mark had childhood autism. The physician apologised for upsetting her and she replied, 'It is not upset, it is relief! Absolute relief. We have an answer after 37 years'. Not only was it a relief but it provided answers for previous unexplained behaviour patterns and limitations Mark had exhibited over his life course. Often after years of seeking a diagnosis parents felt their perceptions of a problem with their child were finally substantiated, the problem was recognised and a cause identified. Moreover, they had a name for it and expected information, advice and support. For Kate, an adult with ASD, to finally have a medical explanation at 37 years of age and the understanding that ASD could explain her differences and difficulties were validating and relieved her of making excuses.

'Now, I know that this is something intrinsically wrong with me and I don't have to constantly make excuses'.

Kate, 40-year-old adult with ASD

Kate felt the diagnosis substantiated her odd behaviours and limitations in social understanding and skills, for which she had spent years compensating. Moreover, siblings expressed the diagnosis authorised the problem. Nancy, 47-year-old Neal's sister stated, 'we always knew something was not right, but it is only recently we knew what'. Nancy explained that the process took about five years to get a diagnosis of autism for Neal, at the age of 44

years. Adults with ASD, parents, and siblings expressed greater understanding and clarity of behaviours and limitations from the confirmation of a diagnosis of ASD.

Furthermore, the process of understanding and accepting a diagnosis of ASD in adulthood was not a universal occurrence. Not all parents accepted the diagnosis of ASD when it was given. Ninety-one-year-old Olivia, mother to 65-year-old Owen, said she is still not sure about this diagnosis,

‘I wouldn’t say I am against it, but when I found out that Owen was on the autism spectrum I was really shocked. It is still such a shock for me and I tend to think it is just his personality, the way he is’.

Olivia, mother of 65-year-old Owen

Owen was diagnosed with ASD at the age of 46. A lack of general societal knowledge of autism was commonplace in the 1950s and 1960s, when Olivia was raising her children, and she may still be unfamiliar with it now, at 91 years of age. Perhaps it is her age and lack of understanding of autism or Owen’s age that makes it hard for her to accept the diagnosis. After all he succeeded at, and retired from, a career in the public service and has lived alone for 36 years.

However, difficulty accepting the diagnosis of ASD was not confined to the parents of adults in the older age group. Fiona described how when her 27-year-old son Frank was diagnosed she and her husband did not initially accept it.

‘When he was first born we didn’t realise anything was wrong. He was slow to develop physically and that was put down to dyspraxia. We didn’t actually get a diagnosis until he was about 3, but we chose to ignore it because we disputed it at the time’.

Fiona mother of 27-year-old Frank

Frank’s parents continued to dispute his diagnosis of ASD until as a teenager he became a school refuser and needed more support. Seemingly, his parents denied his diagnosis until his needs for support exceeded theirs and the school’s capabilities. At this point Fiona described seeking ASD specific support services for Frank and so at the age of 15 years he received a statement of educational need and changed schools. Frank has multiple developmental, social and communication problems, and Fiona acknowledged that after a childhood spent denying he had ASD, in his adolescence she finally did accept the diagnosis. She now feels the

diagnosis has helped her and Frank to understand what it is that makes him different and the best ways to support his strengths and limitations.

Additionally, not all adults readily accepted a diagnosis of ASD when it was given. Twenty-three-year-old Elliot received a diagnosis of Asperger's at the age of 15 years. He recalled an adjustment process to accepting the diagnosis.

'I shied away from reading anything about it, because I didn't want to be labelled or categorised and I didn't think reading a book would teach me anything about myself. It probably would have. It definitely would have given me a foundation to look at and compare myself to and see where I do struggle'.

Elliot, 23-year-old adult with ASD

Elliot explained it took him 'at least a year' before he came to terms with the diagnosis. The responses of family members on receiving a diagnosis varied from empowerment to difficulty accepting the diagnosis and even denial. For some parents and adults with ASD it was a process of acceptance of the diagnosis. Accordingly, a diagnosis of ASD is more than just a validating label; it can be a signpost for support.

The underlying purpose of a diagnosis in general includes the expectations of interventions, cures and a prognosis. A diagnosis of ASD brings information about behaviour and development and may create a road map for interventions and access to specific services. Parents ultimately wanted to understand why their child exhibited certain differences and how they and others could provide help. Helen, 23-year-old Harry's mother, explained that once he received his diagnosis she 'threw' herself into finding information and ways to help him.

'We got him into a special school and from there he kind of found his groove and developed as a person. From where we started he has come on leaps and bounds'.

Helen, mother of 23-year-old Harry

Although there is no cure, standard treatment protocol, or universal prognosis for ASD, the diagnosis provided understanding, information and for most younger aged adults with ASD, educational support in childhood. Having a diagnosis of ASD for a child can enable parents, as well as others, to understand and support the child better. As reported by participants in the older age group, not knowing what is wrong can add to a parent's stress and make it hard to know what to do. A diagnosis formed the basis of understanding and action. With no

answers not only did a parent not know what to do or expect, supportive services that could help the child may not be accessible without a diagnosis. Most older aged adults with ASD did not receive any formal social support as children, such as educational support, nor did their parents receive any respite care. Yet, receiving a diagnosis in adulthood did improve understanding and end uncertainty. Moreover, having a diagnosis and the knowledge it brought enabled some family members to recognise the support needs of their family member with ASD, to develop positive coping strategies and to plan ahead for future support. However, although receiving a diagnosis of ASD was widely viewed positively by adults and family members, social difficulties and limited opportunities remained. Within communities adults continued to experience discrimination as a result of a lack of understanding about ASD in adulthood. The tolerance that is extended to children with ASD was often lacking. While ASD in childhood and adolescence is receiving substantial attention in the scientific community, educational systems and from the press, adult ASD and related issues largely remain neglected. Additionally, while a diagnosis and information about ASD decreased uncertainty, all was not solved; a diagnosis did not equate with service support for adults with ASD.

The analysis of the transcripts in regards to the concept of receiving a diagnosis highlighted not only what it changed but also what it did not change. Older aged adults with ASD, who had previously been undiagnosed or misdiagnosed in childhood, received a diagnosis in adulthood because of changes in societal context, ASD diagnostic criteria and awareness. However, underlying the expressions of relief and validation was the disappointment of how little it changed the lived experience. It was the same, only different because now they had a reason, yet they remained living in a state of liminality, unrecognised within the social context and unsupported by services. For most older adults getting a diagnosis did not provide a pathway to services, other than financial support in the form of disability income. They either did not meet the criteria for social support and/or there was no availability of support services where they lived. Moreover, for younger aged adults who had received an early diagnosis once they reached adulthood support services were not available. Grace, 24-year-old George's mother, stated, 'There is no one backing them up and it is a crime. It is like at 16 you are cured'. Unable to access the support they need, adults with ASD remain reliant on

family members. Peter is 38-year-old Paul's father. Paul received a diagnosis of ASD at the age of 30 years. Peter expressed the limited availability of support services for Paul.

'Social services have a care plan for him, but it is just a piece of paper and they don't do very much. They are cutting back on everything. All kinds of organisations have lovely statements about their standards but when you experience it or check it out, it does not happen.'

Peter, father of 38-year-old Paul

Paul did not receive support services growing up and now as an adult his support needs are either met by his father or remain unmet. The boundedness of levels of need that constitute access to social services left support inaccessible to many other participants as well. Many did not meet the eligibility criteria to qualify them for support services. Without a high level of support need, a learning disability or serious comorbid psychiatric condition, most participants 'fell through the cracks' of social support services, living in a liminal state betwixt and between with no formal support. Indeed, the social context of ASD is in a state of transition and this pioneering cohort have yet to be recognised or supported to enable them to fully engage and contribute to their communities. Age, severity of symptoms and level of need appear to influence outcomes in diagnosis and support and will be discussed next.

#### **Within age groups differences of diagnosis**

Most adults with ASD shared similar experiences in the process of diagnosis to others in their age group; however, some significant within age group differences were identified. Fifty-six-year-old Liam was the only participant in the older age group to receive a diagnosis of autism as a child at the age of 4 years. His mother described that he did not communicate verbally until he was 5 years old, that he was very sensitive to sound and displayed odd behaviour.

'He was scared of any noise; if he heard a door creaking it upset him. If he thought someone was going to close a car door he would block his ear. All sorts of things frightened him and he could not tell us why. As a small child he did all sorts of autistic behaviours. He picked up strings in the street and had a way of playing with them again and again [motions to twirling it].

Lucy, mother of 56-year-old Liam

The severity of the presenting symptoms of 56-year-old Liam are aligned with the narrower diagnostic criteria of the mid-twentieth century when he was a child and may explain his early diagnosis. Lucy explained that Liam began attending the Sybil Elgar School at 5 years of age. The Sybil Elgar School was the first day school for autistic children in London opened in 1965. With the diagnosis of autism Lucy obtained a reason for his difficulties and Liam

received educational support. Liam continues to live with his mother, who is 91 years of age and he volunteers at a community centre 3 days a week. As an adult he receives a disability allowance but no other community support services.

Derek is the oldest adult in the younger age group at 29 years of age and the latest to be diagnosed at the age of 27 years. His diagnostic experience is more similar to adults in the age group 30 years and older who had unknown explanations for their differences. Derek's mother expressed feeling unprepared to cope with the stress and difficulties she faced in raising her son and described how her efforts to seek medical answers resulted in greater confusion and anguish.

'Right from the beginning when he had his 6-month developmental test, they thought he was deaf. Then they told me he was a floppy baby, a late developer and that he will progress and grow up fine. Because I didn't initially have a diagnosis when he was younger, it was very, very stressful. It was very challenging because he had a lack of communication, if something was wrong he could not explain himself and so he would have a tantrum. And I used to feel exhausted because these outbursts could happen at any time.

Diana, mother of 29-year-old Derek

Diana's experiences in the process of seeking a diagnosis and in raising her son is analogous with other parents who had an unknown diagnosis. Moreover, his age places him in the social historical environment with limited knowledge and awareness of ASD. Change and awareness may be a slow process occurring at different times and places at various levels of society. However, the assignment of age groups in this study was established partially based on changes in the scientific and medical knowledge of autism and social awareness and so may not accurately reflect changes in different areas of England. ASD services and support where Derek grew up may have been more limited than in other areas. In contrast, Frank who is 27 years old received a diagnosis of ASD at age 3 years. Similar to Liam, Frank displayed severe developmental and behavioural difficulties as a young child, while Derek presented with more nondescript symptoms in childhood. Age and severity of presenting symptoms influenced the acquisition of a diagnosis of ASD in childhood and the receipt of specific information and support for adults with ASD and their family members. The older aged adults with severe developmental delays and limiting behavioural issues received a diagnosis of autism at an earlier age than their peers who presented with less severe more

ambiguous symptoms. Likewise, severity of presenting symptoms resulted in a diagnosis of ASD at an earlier age for adults in the younger age group. However, unlike the older aged adults with ASD, all but one participant in the age group 18-29 years were diagnosed in childhood or adolescence.

In summary, distinct differences in family experiences of diagnosis were noted by age group based on the concepts of unknown or known. Moreover, these distinctions reflect the life course theory perspective of the influences of historical social context. Evidence suggested the concepts of knowing or not knowing a diagnosis of ASD are reflected in the historical and social understanding of autism at the time when adult participants were children. The micro, meso and macro (family, community and society) environment influenced the experiences of diagnosis for participants. The majority of the older aged adults with ASD and their families were included in the category of unknown, without a childhood diagnosis of autism. Key findings of their experiences reflect the historical time of the lack of awareness of autism and included misunderstanding, blame and stigma. A more experiential and intuitive response to not having a diagnosis of autism was expressed by family members. Additionally, as a result of lack of information and support, parents said they were self-reliant and resilient in raising their children. The experiences described by older adults with ASD and their family members depict lives lived in a liminal state with external and internal restrictions. Most younger aged participants represented the known, with a diagnosis of ASD received in childhood. Better social and medical awareness of ASD, and wider diagnostic categories when they were being raised, contrasts the historical environment of the childhood of older adults. As a result, the experiences of the majority of those in the age group 18-29 years encompassed better support, less stigma and blame, and more information and professional interventions. Parents described less experiential coping and self-reliance and more guidance through information and support services. Additionally, the personal meaning diagnosis provided included relief, acknowledgement, knowledge, information and awareness. However, the practical experience of a diagnosis of ASD in adulthood was one of indifference, with little community or societal support available for adults with ASD other than financial disability support. Consistent with quantitative findings, most participants regardless of age remained highly reliant on their parents to meet their support needs. Parents continued to provide functional and emotional support to their adult children with ASD. The functional support parents

provide is discussed in greater detail in the following chapters. The emotional support parents give was central in the theme of mental health, discussed next.

### **The persistence and impacts of mental illness**

As the interviews with parents, adults with ASD, siblings and partners progressed the issue of mental illness was repeatedly expressed. Although no questions or prompts with respect to mental wellbeing were asked directly in interviews with adults with ASD and their siblings, participants spoke universally of enduring mental illness in adults with ASD across their life course. As experiences with mental illness were detailed in interviews what became evident were the challenges and limitations it presented above and beyond those imposed by ASD. This section first outlines family members' past recollections of enduring mental health problems, then it proceeds to detail the functional limitations imposed on the adults with ASD by mental illness. It ends by describing the future concerns for the safety and mental wellbeing of adults with ASD when continuous emotional support provided by family may be absent. Clear differences in age group experiences of mental illness were not evident in the qualitative analysis because almost everyone had been affected by it.

For many adults with ASD the unmet need of *other mental health problems* identified in the quantitative findings was a central focus in the interview and seemed to consume their daily lives. High levels of anxiety and other mental health problems appeared to be unmanaged medically and interfered greatly with everyday activities. Not only do the findings of the qualitative interviews confirm the high levels of mental health problems reported by adults with ASD in the CANDID questionnaire, they add knowledge of the experience of mental health issues for adults with ASD across the life course and from a holistic family perspective. Moreover, influential and interconnected exchanges between family members in regards to mental wellbeing highlight the linked lives principle of the life course theory, as described in Chapter 1. The linked lives principle asserts that people in salient relationships with each other, such as parents and children, occupy mutually influential interwoven pathways that extend throughout their lives (Elder et al., 2003). Many family members described continuous emotional and functional support for adults with ASD across time and through social changes. This was particularly evident in reported efforts to maintain the mental wellbeing of the family member with ASD.



### **Looking back: anxiety and stress a constant**

Mental health disorders are not part of a person's ASD, yet the persistence of mental illness was expressed in each family's interviews. As discussed in Chapter 3, previous research shows high comorbidity levels of mental illness and ASD. Most parents and other family members expressed providing an emotional safety net for their relatives with ASD in an effort to keep co-occurring mental health issues at bay. For example, mothers described consistently providing emotional support for their child at school and cajoling them along in adulthood to avoid depression. Forty-seven year old Neal's mother, Norma recalled, 'all the time I was boosting his morale, because he would go very depressed just like that. There is no in between, he is either up or down.' While Mark, an adult with ASD, stated that he had not been 'down for a while', he added 'Mum always does things to try and cheer me up'. These statements illustrate not only the constant struggle, but also the adults with ASD's susceptibility to experiencing mental illness. Furthermore, it highlights the continuous process of the linked lives of parents and their child with ASD.

Almost all adults with ASD explained how debilitating and isolating anxiety, depression and other mental health problems had been for them throughout their lives. Although the severity or duration of the symptoms were not detailed, participants stated experiencing draining effects, including decreased energy and fatigue, loss of interest and appetite. Many described anxiety as a constant in their lives. Owen is a 65-year-old man with ASD, who lives alone. He was not diagnosed with ASD until adulthood. He described his comorbid psychopathy and emphasised that anxiety was his principal concern.

Like a lot of other people with autism, I have other problems apart from autism. I suffer from Obsessive Compulsive Disorder which is common in people with autism; and not only that but, generalised anxiety disorder. Anxiety is my biggest problem.'

Owen 65-year-old adult with ASD

It is telling that Owen used the term 'suffer'. He seemed to suffer from his 'other problems' of comorbid mental health conditions with the challenges of these co-occurring mental illnesses being more debilitating than his ASD. ASD affected Owen's ability to communicate and socialise but the restrictive behavioural patterns of his Obsessive Compulsive Disorder and

overwhelming anxiety caused him to withdraw even more than usual from social encounters. Moreover, he emphasised that anxiety has been a constant all of his life with no abatement.

Often parents identified the struggle and toll mental illness caused their children. Some described distressing experiences at school due to high anxiety levels and others the impacts of fears, depression, phobias and obsessive compulsive disorders. Elliot was 23 years old, lived at home with his parents and had never been employed. His mother expressed being distraught seeing Elliot just 'lying on the sofa' or 'up in his room for days'. She reported that 'for the last few months he has been really down, really moody, not showering or wanting to eat'.

'He is really struggling to keep up with things. His self-care is erratic and I think he would like to kind of disappear. He is just not holding the basics together.'

Emma, Elliot's mother

Emma defined his 'struggle' related to the comorbid mental issue of depression. Elliot's symptoms of depression were incapacitating, affecting every aspect of his daily life. The parameters of mental illness and ASD often seemed to be intricately intertwined, compounding the needs of these adults. The fragile mental health of their adult son or daughter with ASD was for some mothers an all-consuming need. Grace, George's mother, expressed how his mental health absorbed her time and restricted her attention to the present day.

'With his mental health, it is more trying to get through a day than to think ahead'.

Grace, mother of 24-year-old George

This statement addresses the tenuous state of George's mental health and exemplifies the complexity of the liminal space of planning or not planning for the future. Grace implies knowing plans need to be made but not being ready or able to act on making them. She further explained how isolated at home George was as a result of his overwhelming anxiety. He would spend most of his time alone at home because being around other people was just too difficult.

Moreover, episodes of mental health problems were also reported to be experienced by other family members. A few parents reported personal episodes of mental illness, particularly depression, throughout their lives. Whether these parents had a predisposition of mental

illness or if it was initiated by the heightened stress they identified in parenting their child is not known. Mothers in particular reported assuming the significant role interacting with their child and they expressed almost daily frustrations. Diana recalled experiencing a period of depression when her 29-year-old son Derek was a child. She described the stress and demands of parenting him, emphasising the unpredictability of his 'behavioural outbursts' and having to cope with his 'tantrums'.

'When he [Derek] was younger, I did have a period when I did suffer a lot. I was quite depressed and there was a period of time when I was taking antidepressants.

Diana, mother of 29-year-old Derek

Diana's own experience with depression may have compounded her difficulty parenting Derek. Derek did not receive a diagnosis of ASD as a child. Not knowing the cause of his frustrations and behavioural reactions added to Diana's stress. Moreover, without a diagnosis of ASD, no individual or family autism support was received.

Past episodes of depression were also reported for a number of siblings of adults with ASD. Emma described that Elliot's only sibling, Eric, had endured bouts of depression. Eric is five years older than Elliot, his brother with ASD. Emma expressed her concerns about Eric's future ability to support Elliot when she and her husband are no longer able to maintain support.

'He worries, 'will I have to fend for Elliot when you are gone; will he still not be able to manage life by himself?' I know he worries about these things and he has had a lot of depression himself.'

Emma, mother of 23-year-old Elliot

Emma insinuated the expectation that Eric would continue provisional support for Elliot post-parental care. The link of support between family members, as recognised in the life course theory, crosses generations and is illustrated in Emma assuming Eric will support his brother when she and her husband cannot. Depression in particular seemed to be experienced by multiple family members in some participating families and may affect the ability to provide future support. As such, adults with ASD, their parents, siblings and partners reported the excessive emotional and physical impacts other mental health problems presented beyond those of ASD.

### The overwhelming functional limitations of mental illness

For some, '*other mental health problems*' has been and continues to be a barrier to engaging in social relationships, seeking employment, and handling changing circumstances. Many participants explained how debilitating and isolating their mental health problems were. Overwhelming anxiety restricted adults with ASD's ability to socialise or work outside the home. George, a 24-year-old man with ASD, expressed he would rather stay confined in his home than go out and put himself in stressful situations and have to interact with people. His social anxiety is so great that self-imposed isolation is preferable. Moreover, it is functionally debilitating, as he is unable to seek or manage employment, or relationships outside of the home. William a 44-year-old autistic man who expressed social anxiety was his biggest problem, described how he avoided having to interact with people.

'As soon as I step outside I put on headphones so that eliminates people talking to me and I often go out only when it is dark. The headphones form a certain barrier and if people do try to talk with me, I pretend I don't hear them; so it is a coping strategy I have developed.'

William, a 44-year-old with autism

Using this coping strategy, William was able to leave the house, yet his anxiety restricted and dictated his outings and abilities. As such he lives within a space between isolation and interaction with his community; a liminal state of betwixt and between. The distress of possible social interactions created an invisible barrier that socially isolated these adults. Their mental health disabilities are complex and not immediately evident to others. Adults with ASD and their family expressed wanting to have their needs understood and explained simple accommodations that would enable them to function better in the community. For example, Matthew, the sibling of Mark, an adult with ASD stated, 'He can't wear a badge, that itemises his needs, but somehow people need to know he needs more time and space, so that they can make allowances'. Diana, 29-year-old Derek's mother said, 'Unless people understand ASD or they know Derek, they look at him and think he should get up and do it'.

Mental health problems were identified as both a restriction to employment and a result of unemployment by older adults with ASD. Kate reported that she would like to be employed part-time but felt that her fragile mental health restricted her abilities.

'Who would employ me? I will have a bout of illness and it stops me from doing most things. The depression kicks in and I start feeling tired and unmotivated.'

Kate, a 40-year-old adult with ASD

Kate lived with her mother and had never been employed. She expressed her mental health limited her employability. Mental illness was also suggested to be a result of unemployment for some participants. Adults with ASD and family members expressed the onset of mental illness arising from job losses and extended periods of unemployment. Without the structured routine and social contact of a job, descriptions of ‘spiralling into depression’ were recounted. For example, the experience of losing his volunteering position initiated a mental health crisis for Liam.

‘It was a very stressful event and it triggered my worst mental state. Because of my depression and anxiety problems from one month to the next it all went downhill.’

Liam a 56-year-old adult with ASD

Although it was not a paid position, the loss of the routine and social encounters distressed and humiliated Liam. He reported blaming himself, distancing himself from his mother and sister and becoming very depressed.

The overwhelming sense of anxiety and other mental health problems of their adult child with ASD also pervaded the lives of parents on a daily basis. Many parents and adults with ASD are seemingly confined to living in the moment, getting through the day without a crisis and unable to prepare, plan or look forward to the future. Diana compared how restricted her life was to that of her friends whose adult children had left home. She described them as ‘free agents’ able to do whatever they pleased when they wanted to.

‘With Derek, I never know what is going to happen from day to day. He can become very depressed and is a constant worry.’

Diana, mother of 29-year-old Derek

Diana felt her life was restricted and social contact decreased by attending to Derek’s emotional and functional support. Parents and other family members expressed the mental wellbeing of adults with ASD was a prime concern for the future when they are unable to provide ongoing emotional support.

#### **Looking ahead: vulnerabilities and concerns**

Most parents voiced concern for the future mental health of their adult son or daughter with ASD. Their children’s past and present experiences of mental illness justified their worries. Moreover, current unmet mental health needs heightened parents’ worries for the future,

when they are not able to support or advocate for their child. Kay's 40-year-old daughter with ASD Kate reported having high anxiety, suffering with depression and having a hoarding condition. Kay extrapolates Kate's current unmet needs of mental health support, into future concerns for her mental wellbeing.

'She still struggles with mental illness and feels the doctor minimises her complaints. It is her poor mental health that limits her potential and isolates her. She has suffered a lot. It is also a massive worry for me. She doesn't seem to be taken seriously. That is my greatest fear for her future.'

Kay, mother of 40-year-old Kate

Kate lived with her mother. On bad days she stays in bed and sometimes does not leave the house for long periods. Their living conditions are not ideal with items cluttered and piled high in the corridors and rooms. Additionally, they have seven house cats. Kay worries who will intervene and support her daughter in the future. Family members feared the precarious mental health of adults with ASD could place them at risk of a mental health crisis in the future when a parent dies or family support is diminished or unavailable.

Rebecca is 51-year-old Robert's partner. They have been together for over 20 years. Robert is autistic. Rebecca did not feel that Robert would be able to manage without the support that she and their relationship provides.

'I don't think he would feed himself and he wouldn't get out of bed. He can't cook. He would get very depressed.'

Rebecca partner of 51-year-old Robert

Robert's mental health was the focus of Rebecca's concern if in the future she was not able to provide him the support she does currently. In her eyes the risk of depression and not his inability to cook posed a greater threat. Seventy-year-old Peter, Paul's father, is in poor health. Although Paul, a 38-year-old autistic man, lives independently, he eats his evening meal with his father and depends on his father for support in a number of areas including emotional support. Paul struggles with anxiety and has experienced episodes of acute mental illness. Peter is worried about Paul's mental health when he dies.

'He worries about me and I find it hard to talk to him about the future. We support each other and emotionally he will suffer. I do worry that he could have a mental health relapse.'

Peter, father of 37-year-old Paul

Peter expresses the interdependence of his relationship with his adult son Paul through mutual support and the difficulty of discussing the subject of death. He worries that the loss of the daily emotional and functional support he provides to Paul may precipitate a mental health crisis. Peter described how the geographical distance of Paul's only sibling, his brother who lives in Asia, adds to his concerns. He stated Paul's brother will not be able to assume the support that he has provided to Paul for years. Although Peter acknowledged Paul's brother may be able to offer some emotional support, he emphasised that there were no other relatives available to take on the everyday responsibility of helping Paul. The close relationships and support provisions of family members expressed in the interviews reflect the linked lives principle of the life course perspective. The fears for the future mental health of adults with ASD expressed by family members underscored the possible absence of this linkage over time. This is discussed in more detail in Chapter 9.

Three key messages summarise the issues surrounding mental illness for families affected by ASD. First, adults with ASD described a lifetime defined by mental health issues. Second, long-term anxiety and other mental health problems limited adults' ability to live independently, secure and maintain employment and relationships, over and above their ASD. The comorbidity of a mental illness caused adults with ASD to withdraw more than usual from others and decreased their motivation and interest in activities. Third, the consistent emotional support family members provided across time to maintain the mental wellbeing of adults with ASD displays the linked lives of salient relationships, as well as worries for the future when these links are missing. The family presented as a micro social group that sustained and buffered the mental wellbeing of adults with ASD within the macro social context. Moreover, the emotional support they provided linked their lives between and across generations.

## **Chapter summary**

The overarching, significant contribution of these findings to the literature on ASD is to highlight changes over time in the diagnostic criteria and process, improvements in social awareness, a void in services and a lack of supportive social environment for adults with this condition. Greater awareness and broader diagnostic criteria may have contributed to most of the older adults with ASD receiving a diagnosis in adulthood and the younger adults with

ASD primarily in childhood. Additionally, findings suggest the pathway to a diagnosis in adulthood can be through mental health services, social crisis, or judicial trouble. However, findings also underscored how a diagnosis of ASD in adulthood provided little in the way of formal support, leaving family members attempting to fill the adults' support needs. While there have been recent improvements in service provision, many gaps and barriers remain, resulting in adults with ASD not being able to access the range of support and services they need.

Additionally, high unmet needs of comorbid mental illness were reportedly unaddressed in this sample. They may have never had their mental health needs thoroughly identified or failed to have them reassessed as they age and experience stress at different life stages or events. One reason could be that mental health issues often present as behavioural problems. They may then be treated for behavioural problems without identifying or treating the underlying mental health need. Adults with ASD who present as high functioning may deny or use their strengths and skills to mask their mental health difficulties. The adjunct of a co-occurring mental illness for adults with ASD may increase their vulnerability and place them at greater risk of harm. Future concerns for the wellbeing of participating adults with ASD were universally expressed by family members.

The themes of diagnosis and mental illness set the stage for subsequent chapters of interpersonal relationships and welfare. Participants' experiences in these areas are immersed within and influential to these other aspects of their lives. These social relationships of adults with ASD will be explored in the following chapter.



## **Chapter 8: Relationships: the limited social networks of adults with ASD**

Social relationships were one of the highest areas of need and unmet need reported by adults with ASD in quantitative measures in this study. Moreover, the persistence of mental health comorbidities across the life course expressed by adults with ASD in the preceding chapter may, along with other factors, influence their social relationships. This second qualitative chapter was to subjectively explore the domain of social relationships for adults with ASD in regards to support needs identified through quantitative analysis in Chapter 6. This addressed the research question (iv) identifying the patterns of relationships and interactions of adults with ASD, as well as research questions (i) and (ii) ascertaining their support needs, and how, and by whom, they are being met. As discussed in Chapter 1, ASD is a social disorder which effects social interactions, verbal and nonverbal communication, interests and behaviour with individual variability (Rapin and Tuchman, 2008, Tager-Flusberg et al., 2005). Verbal abilities fall on a continuum from no spoken language to adequate expressive language and nonverbal communication difficulties include understanding social gestures, facial expressions, body language and tone of voice (Klin et al., 2007). Impediments in social communication and deficiencies in social skills impact social interactions (Timler et al., 2007). For example, an adult with ASD may desire to interact with others but lack social competencies to initiate and sustain conversations or engage in social activities. Moreover heightened sensitivities and social anxiety associated with ASD may result in social avoidance or inappropriate behaviours (White and Roberson-Nay, 2009). Previous research has identified limited peer relationships and diminished recreational activities among adults with ASD (Orsmond et al., 2004) and inadequate opportunities for employment and residential living (Graetz, 2010). Less research has distinguished the family relationships and interactions of adult with ASD. This chapter addresses the research aim to explore how current and future support needs of adults with ASD are being, and plan to be, met from the perspectives of family members.

The domain of social relationships incorporates seven areas of need relevant to social interactions on the CANDID that were grouped together in this study for quantitative analysis: social relationships, communication, inappropriate behaviour, daytime activities, sexual expression, safety of others and caring for someone else. In the CANDID, the area of

highest reported need by adults with ASD was social relationships, with significant difference between the two age groups: older participants reported a greater need. Three other social areas were reported as high need: communication, inappropriate behaviour and daytime activities. Qualitative data added depth and detail, qualifying the collective patterns of social interactions reported by adults with ASD in these four social areas of greatest need.

Interview questions broadly asked participants to describe interpersonal relationships within and outside the family. Although quantitative data revealed significantly greater need in the area of social relationships for older adults with ASD than younger adults, no substantial age differences were evident in the qualitative analysis. Moreover, inappropriate behaviour, reported highly in quantitative analysis, did not feature centrally in qualitative interviews. Participants routinely identified behavioural restrictions and preferences for sameness as problems that needed to be acknowledged and accommodated for if possible. For example family members described an adult with ASD's need for rigid structure and routines and adapting family relationships and activities accordingly. Other reports of inappropriate behaviour of adults with ASD were described in association with their sensitivities and limited social and communication abilities. Communication difficulties and limited social skills of adults with ASD were described by all family participants. Qualitative analysis underscores the complexity of social relationships and interactions for adults with ASD and the subtleties of social deficits. The social deficits of adults with ASD presented the biggest area of challenge for them and for support provision.

Family member interviews yielded both retrospective and prospective data about relationships and support. Findings contextualise the life course theory principle of linked lives between family members and across time. The life course perspective, as described in Chapter 1, is a theoretical model that considers how chronological age, social interactions, life transitions, and social change shape people's lives from birth to death (Elder et al., 2003). The principle of linked lives emphasises interdependence and the ways in which relationships can be a source of both support and control (Hareven, 1977). Social relationships for adults with ASD are described in reference to the life course perspective and explained through the concept of liminality introduced in Chapter 7.

The findings are organised within one overarching theme generated through the analytic process: limited social networks. The theme of limited social networks is critiqued using the social capital theory concepts of bonding, bridging, and linking networks. From a sociological perspective, social capital is conceptualised as relationships and social networks, and the resources they provide (Coleman, 1988, Coleman and Coleman, 1994). Relationships and resources of social networks extend from bonding interactions and support within the family, to bridging network connections through social engagement in the community and employment, to linking networks involving influences of hierarchical social structure and institutions within society (Falk and Kilpatrick, 2000). Social networks include positive attributes of relationships and resources, as well as consequences of restricted access to opportunities. The concepts of bonding, bridging and linking social networks have been used in economics, business, political science, public health and the social sciences (Brian, 2007). However, to my knowledge, they have not been used to describe the social networks of adults with ASD.

The main assertion is that social networks have value to an individual or group. Those with well-developed social networks, particularly bridging and linking networks, are better able to mobilise resources to pursue desired outcomes (Agnitsch et al., 2006). Additionally, Burt (2000) describes social capital in terms of advantage and inequality, with individuals who are more intelligent, attractive, articulate and skilled more likely to be advantaged. Communication deficits and social limitations of adults with ASD may be a disadvantage to building bridging social networks and accessing hierarchical societal links within the community. However, although a bonding network may provide a social safety net for individuals with ASD, particularly if formal services are not available or accessible, informal family support may diminish across the life course. Findings from this study are framed within the social capital framework of bonding, bridging and linking social networks to describe the relationships and social structure that comprise the informal and formal resources and support available to adults with ASD.

The theme of social networks maps onto the research aim to understand the individual support needs of adults with ASD, how and by whom support needs are met, as well as by embedding the support needs of adults with ASD within the wider context of family

relationships and social experiences. Additionally, social networks have implications for how and by whom future support may be met. Social networks can provide social support in the form of emotional, instrumental, and informational support, as well as access to other resources. Deficits in social support have been associated with a wide variety of adverse health outcomes in older age, although not specific to adults with ASD (Uchino, 2006; Reblin and Uchino, 2008), ranging from physical health to depression and self-harm (Dennis et al., 2005). Findings may inform the need for conversations with adults with ASD about usual or important connections, such as identifying activities, key people, and significant places. Additionally consideration of how connections enhance or hinder wellbeing, and discussions on what might be changed for the better and how could be discussed.

The aim of the analysis was to qualify the bonding, bridging and linking social networks of adults with ASD, and strengths and weaknesses in relationships and the structure of social support and resources available to them currently, and for the future. It focused on understanding the social interactions and experiences of adults with ASD, from their perspective and that of family members. The analytic process consisted of identifying patterns that served to illustrate the varied meanings and representations of the social relationships and support of adults with ASD.

Analysis revealed the social network of adults with ASD consisted of predominately bonding networks, largely confined to a few well connected individuals who are primarily family members. Most adults with ASD had limited bridging and linking social networks outside the family. While most of the social networks described pertain to face-to-face interactions, the cyber social communication and interactions of adults with ASD are briefly discussed. Potential consequences of the limited social networks of adults with ASD are also described and discussed.

### **Defining bonding, bridging and linking social networks**

Social networks are the ties of relatives, friends, and associates that connect people (Cochran and Niego, 2002), and through which people have access to resources and support (Bruggeman, 2013). Resources and support accessed through social networks can span domains to include work or private life and comprise a range of tangible goods, such as

functional support or information, to intangible goods including emotional support and influence (Kawachi and Berkman, 2000). How people access and use resources can be distinguished through three types of social networks: bonding, bridging and linking.

Bonding is the interactive, interpersonal process of forming close relationships (Clark, 1990). Bonding networks are formed between close-knit, relatively homogenous individuals, such as family members and close friends (Hawkins and Maurer, 2009). A dyad or relationship between two people, such as mother and child, forms the building block of a bonding network, but is itself conditioned by the networks in which it is embedded (Williams and Durrance, 2008). For example, the mother-child relationship develops within the socio-cultural context of the family including unique experiences, values, and beliefs, but the family is embedded in and influenced by the community and wider social context, such as economic and social resources. Both internal family dynamics and external societal relationships and resources influence individual developmental and supportive experiences. Bonding networks, developed within families and with close friends may generate the most enduring ties (Wasserman and Faust, 1994). The life course perspective asserts that these ties established between people in salient relationships extend throughout their lives (Elder et al., 2003). Similarly, bonding networks are the 'horizontal' ties between members, created through social cohesion that holds the group together (Poortinga, 2006). The flow of resources that takes place in bonding networks, such as social and emotional support, time, information, and shared activities, has an insular basis and may change across the life course. Putnam (2001) described bonding social networks as crucial for 'getting by', implying making do or managing. Predominantly, parents, adults with ASD, their siblings and partners described strong bonding networks with just enough support and resources for adults with ASD to get by.

The associations, interconnections and resources of bridging social networks extend beyond bonding networks of family and close friends to involve the wider community (Geys and Murdoch, 2010). Although social networks between individuals within the community are developed from weaker connections, such as with colleagues or acquaintances, potentially more opportunities and resources can be accessed through these direct and indirect ties (Lin, 2002). Relationships of bridging networks incorporate who a person is connected to, and how

these contacts are connected to others, with the potential of extending access to broader resources (Borgatti et al., 2009). Consequently, bridging social networks have been described as ‘getting ahead’ (Putnam, 2001, p.20), contributing to an individual’s ability to succeed, achieve or acquire something. Bridging social networks of adults with ASD are described in the current study’s findings through relationships and resources acquired through educational, community engagement and employment opportunities.

Linking social networks describe connections with people in positions of power (Taylor, 2011) and are concerned with linking individuals to knowledge and resources across formal and institutionalised authority (Oliver and Pitt, 2013). They are considered vertical interactions involving a hierarchy of influence on the availability and accessibility of resources and support (Lin, 2002). Linking social networks are embedded in the social and political structure of the society. They include formalised institutional relationships and structures in a society, such as government, the political regime, the legal system, and the health and social care systems (Catts and Ozga, 2005). Linking networks may provide valuable resources through connections to authority and institutions (Lin, 2002). The reported efforts and struggles of adults with ASD and their family members to access formal services distinguished their limited linking social networks.

Relationships and resources of bonding, bridging and linking social networks are neither static (Morgan, 1990), nor mutually exclusive (Hawkins and Maurer, 2009). They change with individual needs and circumstances over time and can provide different resources. The interactions within and between social networks may provide advantages for adults with ASD across the life course. For example, bonding networks may offer safety and security provided by family; bridging networks could extend social interactions and financial independence, and linking networks might influence service provision and social policies. Exchanges among networks can affect the opportunities and choices available for adults with ASD and impact wellbeing, social inclusion and acceptance. However, implicit in the development of social networks is the individual’s social and communicative efficacy. Social and communication skills and active desire to form associations and interactions within social networks are necessary to access potential resources they may provide. Adults with ASD with social and communication limitations may be at a disadvantage to develop social networks and to

acquire essential resources for getting by and getting ahead. Disintegration within and between social networks may narrow access to resources and place adults with ASD at risk of harm and isolation.

Describing qualitative findings within the framework of bonding, bridging and linking social networks situates adults with ASD within the current societal context of awareness, availability and accessibility of support and resources for adults with ASD in England. Although the quantifiable value of social networks may be vague, the implications of current limited social networks of adults with ASD for future relationships and resources are emphasised.

### **Bonding social networks of adults with ASD: ‘getting by’**

#### **Relationships with, and support from, parents**

Many parents and adults with ASD reported having a close relationship. Thirteen of twenty-one adults interviewed continued to live with their parents. Parents described a strong relationship acquired over years of parenting, interrelating, understanding and trying to meet their child’s needs. Moreover, the extended length of time living together and shared experiences across the life course reportedly contributed to the development of a bonding network and linked lives between parents and adults with ASD. The bonding network offered functional and emotional support and security for adults with ASD. For example, at 40 years of age Kate had lived continuously in the parental home. Kate was the youngest of three children and her parents divorced when she was a child. At the time of the interview, she and her mother resided in the family home.

‘I am very attached to Mum. There are things I find very frightening. I can’t cut the apron string, although most people make me feel ashamed to still live with Mum.’

Kate, a 40-year-old with ASD

As an adult Kate described having an ‘attached’ relationship with her mother. Yet, she expresses ambivalence between her need for continued help, support, and accommodation from her mother in adulthood, and the countervailing pressures for independence from the parent-child relationship. She stated that she would like to have a place of her own but she would find it ‘too stressful’, would be unable to manage a number of practical things such as paying bills, and that she would be ‘very vulnerable’. Kate’s past experiences of abuse and

exploitation, deficiencies in understanding nonverbal communication, and limitations with practical daily living skills contributed to her sustained living arrangement with her mother. However, it places her at a disadvantage should she lose the relationship, support and resources her mother now provides. Moreover, Kate reported having few friends growing up, with no friends currently and never having been employed. Kate had only one living sibling, from whom she was estranged. Her mother Kay was 71 years of age; she provided for Kate's practical and emotional needs and safeguarded her wellbeing. She described challenges and awful experiences Kate had in childhood and adulthood, as well as her own struggles in parenting Kate. Yet, she also reported the companionship Kate provided.

I would say that raising her [Kate] has been more of a bounty than a burden. We have had struggles and continue to, but she stimulates and adds to my life and she has opened a new way for me to look at the world.

Kay, mother of Kate

Kate's sustained dependence on her mother has been a core component of the development of a secure bonding network and lasting relationship. However, her statement also highlights the interdependent relationship she has with her daughter. Kay expressed having few social relationships and restricted mobility, with Kate providing companionship and social engagement for her. Strong parent-child bonds were cultivated across time, through collective socio-emotional experiences, and continued social interactions and cohabiting which highlights the core life course principle of linked lives. However, Kate's bond with her only sibling was reportedly broken. Kate and Kay expressed he did not, and would not, provide any future support for Kate.

The lives of parents, particularly mothers and their adult children with ASD, were uniquely linked, shaping and being shaped by each other through interactions and experiences over time. Parents described 'trying times', 'stressful experiences', and 'fighting battles' of advocacy for children with ASD across the life course. Despite reports of high levels of stress and difficult experiences, many parents expressed coping and adapting favourably. For example, although Betty, the mother of 22-year-old Bruce, stated 'it has been difficult', she assuredly said, 'there is no special autistic parenting, it is extreme parenting and we have managed it very well'. However, Betty also reported there had been times when she, 'got things very wrong'. Betty described that aggressive behaviours and temper tantrums



including hitting, kicking, biting, and throwing objects have and can occur when Bruce is frustrated as a result of miscommunication or when he is unprepared for changes, primarily in his routines. She reported that most of his anger is usually directed towards her but that she worries he may hit or hurt someone else during a behavioural 'meltdown'.

Not all adults with ASD reported strong family bonding networks. A few described having contentious family relationships in childhood. For some, poor family relationships continued into adulthood, while others reported improvements. For example, two adults with ASD who lived independently, 65-year-old Owen, and 44-year-old William, reported the absence of a diagnosis of ASD in childhood contributed to family tension and misunderstanding of their behaviours. Both men described strained family relations and limited support from family members in adulthood. William stated he had no link or bond with his family as an adult. He was estranged from his mother, who was abusive when he was a child, his father had died a few years ago, and he had no relationship with his only sibling who lived in Australia. However, William's reported lack of any social bonding network or linkage with family members was uncommon. Most adults with ASD described the majority of social relationships, support, and resources occurred through family bonding networks. However, William's situation may foreshadow future experiences for adults with ASD as social bonding networks with parents and siblings diminish through death or incapacity.

Owen, on the other hand, described improved family relationships in adulthood, receiving primarily emotional support from his 91-year-old mother and two younger sisters. His father had died ten years earlier. Owen explained that his personal self-improvements and an increased understanding of ASD by his sisters and mother had enhanced his relationship with them. Where previously, as an adult, he had very little contact or interactions with his family, in recent years his bonding network and linked lives with his mother and siblings had improved. Although family relationships and resources through bonding networks may be vital in the lives of adults with ASD, personal and interpersonal characteristics including behavioural, communication and social deficiencies may influence their development and sustainability.

Parents described changes in their relationships and roles when children with ASD reached adulthood. Some parents expressed a more adult-to-adult relationship, while others stated they provided more guidance than parenting. Parents acknowledged respecting the dignity of their adult child while simultaneously being acutely aware of their limitations and vulnerabilities. Twenty-four-year-old George, an adult with ASD, had never been employed and lived with his mother and younger neuro-typical sibling. Grace recognised her son's chronological status as an adult, at the same time as she did his difficulties to manage normative adult interactions and functions. She stated that George found change really difficult, but expressed, 'as long as we keep some things constant', he could 'survive'. George was getting by within a family bonding network with the support and relationship of his mother and brother. Grace described the change in her parenting role and relationship with him in adulthood.

'When he was a little boy it was easy to be his Mum taking him somewhere, now I've got to be a little different respecting the fact that he is an adult. Now it is more although I am his Mum, I try not to come over as his Mum. If we do things I am his Mum and his buddy. It is more of an adult/adult relationship than a parent/child relationship.'

Grace, mother of 24-year-old George

Although Grace identified it as an 'adult to adult' relationship, George's status could be described as liminal, suspended between childhood and adulthood, grounded in neither (Turner, 1987). Although clearly no longer a child being a physically developed adult, socially and psychologically he was unable to assume a normative adult status. The liminality of adults with ASD was evident in their relationships, abilities and responsibilities and may have been primarily due to limited social and communication skills, poor mental health and unemployment. As described in Chapter 6 many adults with ASD continued to live with their parents, were unemployed and had high needs in the domains of mental health, social relationships and communication. In many respects the majority of adults with ASD bordered the threshold to adulthood, requiring continued support provided by parents, partners and siblings; with many not assuming adult roles, responsibilities, or having social networks extending beyond the family. Jones and Higgs (2010) suggest that normative age-related stages and expectations have been superseded by pluralism and diversity as new norms. This was evident in parents' expressions of greater acceptance today of adult children continuing to live with their parents. However, more pervasive were the descriptions of disapproval and misunderstanding of the liminal status that adults with ASD embodied through comments

such as, 'Does he still have that?' and 'He looks fine to me' suggesting normative age-related life course expectations still preside. Moreover, unlike the temporary transition process from one stage to another incorporating the liminality described by Van Gennep and Turner (2011), the liminal status of adults with ASD may be prolonged or indefinite without any demarcations of stages. The idea of a maintained state of liminality experienced by adults with ASD attempts to describe their subjective experience of ASD. However, it can also be suggested that the liminal status of adults with ASD is socially induced and that with the right type and amount of support, adjustments, and accommodations they could cross the threshold and assume 'normative' adult roles and responsibilities.

Communication and social difficulties and limited independent living skills added to the complexity of the liminal social status of adults with ASD. Parents and siblings expressed that unobservable limitations of ASD, such as misunderstanding nonverbal communication or deficits in social skills, contributed to the liminality of adults with ASD and heightened their risks of vulnerability. Kay described how her daughter Kate's invisible social limitations have been detrimental.

'She is extremely trustful and that has resulted in a lot of painful situations in which she has been terribly taken advantage of physically and emotionally. She is very vulnerable and cannot determine who is a friend and who isn't. She has difficulty interpreting what people say and mean. In many respects she is still a child in an adult body.'

Kay, mother of 40-year-old Kate

Kate's social naiveté, difficulty interpreting social or emotional cues, and inability to respond appropriately created a degree of helplessness and susceptibility to harm. Moreover, she appears capable, with no defining features to signify she is autistic. Kate demonstrated superb verbal skills which could lead to false assumptions about her social abilities. Individual dichotomies of strengths and limitations further complicated the liminal status of adults and contributed to their vulnerability.

The lives of most adults with ASD and parents remained linked primarily through social interactions and the provision of support and resources. Parents reported their 'work' was 'not done'. Many described feeling pressure to prepare their adult child for the future when they would not be able to support them or intervene on their behalf. Some described efforts to

teach essential life skills such as money management, cooking and cleaning, and others expressed concerns for who would assume ongoing daily supervision to meet needs, such as prompting with self-care. Mothers predominantly provided the majority of emotional, hands on practical support, mentoring and social interactions for adult children with ASD who continued to reside at home.

#### **Adults with ASD in long-term relationships**

Four men with ASD were in committed relationships with women, either married or cohabiting. They stated partners provided the majority of social support and interactions. Support included help with personal care prompting, managing finances, cooking and other household tasks. Men with ASD and their partners reported they had a close relationship and described having a strong, but limited bonding network consisting primarily of each other. Robert and Rebecca met through employment and had been cohabiting for 20 years.

‘Emotionally we are very close, we spend a lot of time together. I would really struggle if I did not have Rebecca. The amount of support that I receive from her is very noticeable.’

Robert, a 51-year-old autistic man

Women echoed being emotionally close and consistently spending the majority of free time with their autistic partners. However, they also expressed frustrations with communication and behavioural idiosyncrasies of male partners with ASD. They described ways of coping and adaptive techniques to calm or diffuse situations of heightened anxiety and behavioural outbursts of male autistic partners. Women explained routines, strict patterns and literal thinking of autistic partners required their patience and good communication skills for success of the relationships. Additionally, 3 of 4 couples described problems with intimacy. Victor and Virginia had been married for 8 years. She described herself as being ‘celibate’, but not by choice.

‘The only thing that has not changed is in the sexual area. That hasn’t changed at all. Victor loves cuddles, holding hands and kisses. We do all that, but as for actually making love it never happened and whether it will, I don’t know.’

Virginia, partner of 53-year-old Victor, an autistic man

Deficiencies in social understanding and nonverbal communication, as well as heightened sensitivities and anxiety influenced adults with ASD’s ability to engage in sexual intimacy.

However, partners identified feeling loved through other displays of affection and interactions in their relationships.

Significant others also expressed concern about the future support for their partner with ASD. Couples described receiving very little or no external support, including from extended family members. Some expressed the elderly age or death of parents, as well as that the great physical distance between siblings resulted in diminished family support. Moreover, couples reported having very few or no friends and none had an established future support plan for partners with ASD. The bonding of adults with ASD in committed relationships was limited primarily to relationships with partners and the support and resources that they provided. Partners of adults with ASD seemed to replace, rather than add to people with whom adults with ASD shared bonds.

#### **Sibling relationships and interactions across the life course**

As described in Chapter 4, sibling relationships are developed within the context of the family. Childhood relationships described by adults with ASD and their siblings fell into two distinct groups. One group reported contentious relationships beyond the norm of sibling rivalry and the second recounted close, agreeable and supportive childhood relationships. Where siblings fell within this division appeared to be irrespective of age differences, gender or birth order. The resources and support siblings described exchanging in childhood included interactive activities, mentoring and safeguarding. Some expressed their relationship had changed across the life course with improvements in adulthood. However, the majority reported decreased interactions and contact in adulthood. Some siblings explained limited engagement resulted from having their own family responsibilities, demanding jobs, attending college or having moved away from the family home. Laura, 56-year-old Liam's older sister, stated that over the years her interactions and engagement with her brother had decreased, 'life gets in the way and I am working and have my own family too'. Several siblings reported feeling more distant from their brother or sister as an adult.

'I feel guilty for not spending more time with him but as I say, trying to juggle everything and its weird now when I do see my family, I don't really talk to him. It is more like me trying to help Mum and Dad sort out his problems rather than spend time with him.'

Debbie, older sister to 29-year-old Derek

Debbie and Derek expressed having a close relationship as children. She reported feeling guilt-ridden for her current diminished participation and engagement in her brother's life. Debbie described being emotionally distant from Derek, with her feelings 'so mixed up and conflicted'. Helping and supporting her parents to attend to his 'problems' was her priority and obstructed the time, engagement and interaction she spent with him. Debbie was acutely cognisant of the effort and attention her parents devoted to caring for Derek which may have compounded her own guilt for not doing more. Additionally, she described her parents as 'sheltering' her from knowledge of the full extent of Derek's personal matters and support needs.

I just only know a fraction really of everything to do with him and I don't really understand sometimes what his problems are and of course it is a worry for the future because Mum and Dad have all the knowledge and if something happens to them, I am stuffed because I don't know.'

Debbie, older sister to 29-year-old Derek

Debbie's limited knowledge of her brother's needs and her more distant relationship with him in adulthood may make it difficult for her to assume some responsibilities of support in the future when their parents are no longer living. Although most siblings expressed anticipating assuming some level of responsibility of support for a brother or sister with ASD in the future post-parental care the feasibility and practicality of assuming this role may diminish over time if contact and engagement decreases and other responsibilities accrue. This suggests that the sibling bonds and linked lives may be weakened over the life course for adults with ASD.

Seven of eight siblings expressed expectations to assume some responsibilities of support for adult brothers or sisters with ASD in the future. One brother, who was a twin of the adult with ASD, and also on the autism spectrum, stated he did not think he would be able to support or be responsible for his brother in the future. He also required support in multiple areas of daily living. Although they were fraternal twins, the shared risk of ASD among twins is higher than it is for siblings of individuals with ASD (Ronald and Hoekstra, 2011). Siblings often expressed feeling duty bound to continue caring for their brother or sister after their parents.

'Hopefully not anytime soon, but when his full time carer, Mum, disappears or when she becomes unable to continue caring, if he is still in the state where he needs constant care, that will be my responsibility'.

Gregory, younger brother of 24-year-old George

Gregory explained that he would support George to remain living in the family home because it was a familiar environment for him. However, although Gregory acknowledged that his mother provided 'full time' daily care for George, he expressed that in the future he would do his 'best to drop by or be on call or whatever'. Although siblings described the functional limitations of their brother or sister with ASD and high levels of current parental support, the future support they anticipated providing was not comparable. The social imagination of planning and envisioning an autistic adult sibling's future support needs and, the roles and responsibilities they may be required to assume, was difficult for them to express. Siblings ambiguously qualified and quantified the amount of support they would be able to provide and responsibilities were not well defined. For example, sentiments included, 'I will do what I can; if I am able'. Although some siblings continued to reside in the parental home with autistic brothers or sisters, most did not, particularly among the older age group. Unfamiliarity through physical distance and diminished interactions may have influenced their knowledge of, and ability to predict their sibling's future support requirements. The undefined future support and resources of the bonding network with siblings makes it difficult to forecast if they will be able to sufficiently meet the needs of adults with ASD. Moreover, how adults with ASD and their siblings negotiate the role transition of future support will be individualised and influenced by interpersonal relationships and resource availability. Yet, in the interviews most siblings reported the social bonding network would persist to some extent into the future.

The demands of adult life including moving away from home, pursuing further education, entering the workforce, or possibly taking on the responsibilities of starting a new family, had loosened the sibling bonding network, even among siblings who expressed close childhood relationships and interactions. Moreover, the extent of resources siblings reported providing for adult brothers or sisters with ASD had diminished in adulthood with primarily emotional support continuing. Bonding networks of adults with ASD predominantly included parents or partners, with more limited relationships with, and resources from siblings. While the lives of most siblings remained linked in adulthood, consistent with the life course perspective, the number of interactions had decreased, along with awareness and understanding of the social and health needs of an adult sibling with ASD. Decreased interactions and diminished

knowledge of needs may impact the ability of siblings to provide future support for brothers or sisters with ASD.

### Close friendships

The relationships of close friends and the resources they can provide are included in social bonding networks. In addition, through wider relationships, friends may provide contact and resources through bridging networks. The question related to social relationships on the CANDID garnered the highest level of need in this sample. The question asks, 'Does the person need help with social contact, and does he or she have enough friends?' The majority of autistic adults stated they did not have friends or that they would like to have more friends. Communication and social difficulties reported of, and by, adults with ASD were subtle, yet had extensive impact on social relationships, particularly outside the family. In childhood, adults with ASD recollected poor experiences with peers, being bullied, teased and excluded. Limited experiences of friendships and poor social skills restricted their socialisation and social interactions with peers. Many parents and siblings recounted the experiences with friendship of adults with ASD growing up as absent or improper.

'He didn't have any friends [as a child]. Kids always looked on him as a bit weird. He did not engage. He does not engage with other people very well. He has always been easily led and even now he will do and say things because he thinks that's what you want. As a teenager he got caught stealing a can of coke from the local shop. He was told to do it by these people that he thought were his friends and that has been his trouble throughout life.'

Mary, mother of 41-year-old Mark

Parents referring to adult children, and adults with ASD themselves, described being easily influenced, wanting to 'fit in' and not understanding the link between behaviours and consequences. Some adults with ASD were placed in precarious situations socially and legally as a result of being taken advantage of by other people and not understanding possible outcomes of deeds. Moreover, parents stated adults with ASD were not even aware they were being manipulated. They explained adult children naively did not understand why people would want to take advantage of them, or lie to them. Some described adult children who had been exploited financially and others physically, by strangers or 'so called friends'. Communication deficits, particularly nonverbal communication, were reported as contributing factors to misunderstanding the intentions of others.



For many, poor social experiences and limited communication in childhood reportedly did not improve with age and contributed to restricted socialisation and few friends in adulthood. Fifty-three-year-old Victor, an adult with ASD, stated, 'I never really did have any friends and that has not changed as an adult'. Adults with ASD explained the struggle and effort it was for them to communicate and interact socially with their peers.

I didn't have any friends at school but maybe only one and I was his only friend and he was mine and we used to talk all about theoretical stuff and looking back he probably qualified for a diagnosis as well. So any friends I did have tended to be on the fringe as well and at work I had black friends or gay friends who were on the fringe of society and some had learning difficulties and it sounds harsh but they are not challenging. When you are in a relationship with a neuro-typical person it is challenging all the time.

William, a 44-year-old adult with ASD

Managing social relationships was described as requiring a great deal of effort for adults with ASD. Some stated it was mentally and physically exhausting. Although all adults with ASD had spoken language ability, social communication and engagement was an effort. Emma, 23-year-old Elliot's mother expressed, 'On the face of it he is very articulate, but he has to work really hard [to communicate] so it wears him out'. She described how Elliot would often have to rehearse a casual social encounter ahead of time, in order to be able to accomplish it and he would need a 'recovery period' afterwards.

Many adults with ASD verbalised personal limitations in social and communication skills to initiate, interact with, and maintain friendships. Some expressed the inability to know who was and was not a friend. Twenty-three-year-old Elliot described 'obsessing over people' and then realising after a while that the other person did not share the same perception about the friendship. Albert, a 24-year-old autistic adult explained a similar situation of 'making fantasies and imagining relationships that aren't really there'. He stated, 'it always comes back to not being able to read people'. Others explained being unable to interpret the meaning of people's behaviour, especially when it was not synchronised with their words. Forty-year-old Kate, described situations where she had misunderstood some men's motives because they were smiling and saying kind things to her. Some adults with ASD described how logical thinking interfered with their development of social relationships. Elliot, a 23-year-old autistic man expressed that his logical thinking and the questions he asked had often been

perceived as insensitive and harmful to developing friendships. Yet, insight or self-awareness of limitations did not appear to help adults with ASD alter or moderate social behaviours and was identified as a 'great source of frustration'. Adults with ASD stated they needed to methodically learn social skills naturally acquired and patterned through social interactions by neuro-typicals.

'It's hard to gauge because I seem to be doing okay but then I will pass certain boundaries or say something I shouldn't and not really notice. I need some techniques to teach myself how to function around other humans.'

Elliot, a 23-year-old autistic adult

Elliot described that he did not know how to be a friend and needed to learn social skills which most people effortlessly develop. Moreover, being unaware of when or how he made social mistakes, Elliot was not able to learn from the experience to not repeat the same mistakes again.

For some adults social communication was viewed as serving a specific narrow purpose without the intention of being a social interaction. Nancy, sister to 47-year-old Neal, explained her perception of his constrained social and communication skills.

'He will interact for whatever purpose the conversation requires, for like buying a book, but then that is it. Just to achieve a purpose, but it is not anything deeper than that. I think (A): he does not know how to do it; (B): he is frightened to do it and (C): he is reluctant to do it.'

Nancy, sister of Neal, an autistic adult

Neal had adequate verbal ability but lacked skills to engage in social communication. He used communication solely to serve a function of acquiring something but not for social or conversational intent. Even within family relationships, Nancy stated Neal would answer a question if asked, but he would not initiate a conversation. Social deficiencies interfered with adults with ASD's ability to initiate and maintain conversations and engage in social relationships.

However, most adults with ASD expressed the desire to have friends and relationships. Many expressed the complexities of social interactions were compounded by high levels of social anxiety. They described difficulty making friends and worried how they were perceived by other people.

‘It is not that I am not interested in people or friends or making relationships, it is just that sometimes you don’t want to look too desperate and then it comes back to knowing when is the right time and how you come across and I worry about that.’

Albert, a 24-year-old autistic man

Albert expressed being anxious about how he was perceived by others. A number of adults with ASD explained being incapacitated by anxiety at the prospect and experience of meeting new people, with a few reporting self-imposed social isolation as preferable to the overwhelming anxiety of social interactions. Some adults with ASD identified wanting to ‘fit in’ with neuro-typical friends and others explicitly stated desiring friendship with other adults on the autism spectrum. Kay perceived that her autistic daughter, 40-year-old Kate, would prefer having friends who were on the autism spectrum.

‘I know she is isolated and wished she had friends. She would like someone who is her ‘own kind’ so that she doesn’t have to work so hard at faking it. A refuge for her armour so to speak. I wish that she had a network of support, but instead she is isolated.’

Kay, mother of 40-year-old Kate

Authenticity and the desire to be accepted as they are, was expressed both by, and about adults with ASD. The effort required to interact with people not on the autism spectrum was described by some adults with ASD as ‘hard work’ and ‘exhausting’. A few expressed that with age they stopped trying to ‘fit in’ and ‘pretending to be normal’. William expressed that as he has aged he became more ‘relaxed’ with being autistic.

‘As I got older I stopped being like a bee constantly banging against the window and trying to adapt and fit in. As you get older you get tired and just give up trying. Now I don’t want neuro-typical friends, because they are too much work and it is too hard.’

William, a 44-year-old autistic man

When William perceived his self-worth as no longer conditional on being accepted by others he described accepting himself. Moreover, his self-acceptance with age reportedly diminished the stress and anxiety he associated with heightened efforts trying to assimilate perceived social expectations and neuro-typical relationships. He expressed being satisfied with relationships and social interactions with people ‘more like himself’ on the autism spectrum. Additionally, 65-year-old Owen expressed having two best friends who were also on the ASD spectrum. One he met years ago in a social skills group and the other through an

advertisement in an ASD magazine. However, he described that social community was missing in his life because currently his friends lived at a great distance.

‘My quality of life would be improved enormously if we lived closer to each other and we could see each other more often.’

Owen, a 65-year-old autistic man

Although Owen stated he communicated with his friends via telephone and e-mail, he expressed limited face-to-face engagement as isolating, and he described ‘feeling lonely from time to time’. As such, personal characteristics and circumstances of adults with ASD may make them vulnerable to social isolation and loneliness. Moreover, accounts of reduced and poor experiences of socialisation and social interactions of adults with ASD raised concerns by family members about possible risks of vulnerability and isolation, particularly in the future when current support provision may change.

Without social understanding, engagement and experiences of friendship in childhood, adults with ASD were ill-equipped to develop strong bonds and social relationships that could provide bridging to wider communities and resources in adulthood. Bonding networks of close friends were reportedly very limited for adults with ASD. A few described having one or two close friends from whom they received mainly emotional support through social interactions. However, most adults with ASD expressed having no social life or ‘true’ friends.

Close knit family relationships and resources through bonding networks provided numerous beneficial features for adults with ASD. Family relationships and the continuity of the resources they provided contributed to the security and wellbeing of adults with ASD. Yet, adults with ASD may be disadvantaged if relationships, resources and support is limited to bonding social networks. With limited socialisation outside of the family, many adults with ASD may be at risk of social isolation, particularly when family and living situations change in the future. Previous research has identified social isolation and low social support as a heightened risk factor for abuse among older people (Acierno et al., 2010). Fifty-six-year-old Liam, who had lived his whole life with his mother, stated his major worry for the future when his mother was no longer alive was loneliness. Additionally, the possibility of social isolation for adults with ASD in the future was also expressed by family members.

‘He has no social contact without me or Mum. He could be a candidate for isolation if he had no support.

Gregory, brother of 24-year-old George

Consistent social and communication impairments, mental illness and diminished social opportunities for adults with ASD may place them at risk of loneliness and isolation. This was a concern for their future that was frequently expressed in the interviews. Optimal support requires clear communication of need, as well as the ability of the support provider to meet the expressed need. Adults with social and communication deficits may be unable to clearly express their needs. Social isolation and loneliness in adults with ASD may be compounded by an underestimation of their needs and a lack of appropriate support services. Unrealistic expectations, misunderstanding or miscommunication of needs can affect the adequate provision of future support. Intended future family support may not be feasible, adequate or preferred for the adult with ASD and their safety may be at risk.

The development of bridging and linking social networks offer broader, more diverse, and possibly supplemental relationships and resources to bonding networks. These social networks which extend beyond the family may provide a supportive safety net for adults with ASD when bonding networks are diminished or absent. They are discussed next.

### **Bridging social networks of adults with ASD: ‘getting ahead’**

Bridging social networks involve relationships with colleagues or associates and resources at the community level. An individual’s skills and abilities may be more instrumental to the development of bridging networks. Few adults with ASD described having bridging networks. The majority of adults with ASD had not attended higher education and were unemployed. This may have diminished their opportunities to develop collegial relationships and leverage possible resources. Moreover, adults with ASD reported little civic engagement and social activities within the community. Communication and social deficits, as well as social accommodations and inclusion, influenced the extent of bridging networks of adults with ASD. Additionally, a number of adults with ASD sought to develop social communication and relationships through computer web sites.

### **Relationships developed through higher education and employment**

Participating in higher education may provide an individual with opportunities to build social bridging networks through the development of relationships that can result in access to resources such as information, emotional support and career networking. However, only six of twenty-one adults with ASD had attended higher educational institutions including university, college and specialist colleges, for example horticultural and art colleges. Yet most adults with ASD described developing no relationships in school or that they were not sustained afterwards.

‘I don’t have a lot of friends at the moment. I had a few friends at school, but I never see them now’.

23-year-old Elliot an adult with ASD

Elliot explained distance and different choices as reasons relationships did not continue. Yet, many adults with ASD reported difficulties making and managing relationships within community settings. Moreover, just one adult with ASD was employed in a position specific to the educational program that was studied and on part-time basis.

Less than one third of the adults with ASD were in paid employment (6 out of 21). One adult was in a full-time position, and five worked part-time. The majority had low level jobs, such as gardening and maintenance, working a few hours a week. Most reported difficulties with social interactions and forming relationships in the workplace. Fifty-three-year-old Victor, the only adult employed in a full time position, worked at a correctional facility and had an undergraduate degree. He stated that he felt his position was below his intellectual capability, but that functionally the position was very structured and he was able to manage the routines. He described how the skills to succeed at school were very different from the skill set needed to succeed in employment.

‘Even though I got a university degree, I failed at my career. Sometimes it haunts me and I wish I could have done that better or got a better job but at the same time I was trying to deal with social problems and challenges that I had and did not know how to correct.’

Victor, a 53-year-old autistic man

Victor stated high anxiety and social difficulties resulted in interruptions in his schooling that extended the length of time to complete his university degree. More importantly he felt they limited his functional abilities and diminished his opportunity to advance in employment. He reported minimal interaction with his work colleagues and stated he had no friends. Sixty-

five-year-old Owen, who was retired at the time of the interview, recalled being downgraded in his civil service position because he could not cope with more than one thing at a time. Owen explained he was a diligent employee but described becoming overwhelmed with anxiety when confronted with multiple tasks or demands. Like Victor, Owen expressed limited interactions and connections with work associates while in employment and no contact with any colleagues in retirement. To cope with the effort and exertion of social exchange one adult with ASD, 44-year-old William, who at the time of the interview was unemployed, described specifically choosing jobs that required very little social interaction. He did not disclose why he was currently unemployed.

‘I was a lorry driver and a post man and they were very male oriented and you worked on your own requiring only minimal social skills when you drop stuff off. As a postman I just plugged myself in [to music with headphones] and did what I had to do.’

William, a 44-year-old autistic man

William’s preference for employment that required little social interaction minimised his need to use social and communication skills, but also the bridging opportunities that such social networks could potentially offer. Psychological, social and communication difficulties reportedly interfered with adults with ASD’s abilities to develop bridging networks with school peers and work colleagues.

Bridging networks may also be developed through community engagement, such as leisure activities, or volunteering. Only three adults reported attending social groups, all ASD-specific, and most expressed little participation in leisure activities. The social groups’ events and meetings described varied in frequency from once a week to once a month. Adults with ASD expressed enjoying them, but family members reported the ASD social groups were insufficient to overcome the social isolation of adults with ASD. Family members described efforts to encourage adults with ASD to meet with group members outside of structured meetings and to attend different community activities, but with little success. Although adults with ASD voiced wanting more friends and social opportunities they were reluctant, or unable to try new things or initiate new social interactions.

Two adults with ASD identified social connections established through volunteering in their community. The voluntary positions offered regular days and hours of work each week and

both described the position as rewarding. Additionally, they expressed enjoying the social contact with staff and other volunteers. Liam described his volunteering role setting out art supplies for children whose parents were attending the centre for advice, counselling, information or support.

‘I have been there [volunteering at community centre] for the last 3 years and it is the best working environment in my experience. The staff are very empathetic and warm. I am treated so kind and everyone is so kind, caring and cooperative. If there was any problem, I could go to anybody.’

Liam, a 56-year-old autistic man

Volunteering enabled Liam to develop social relationships with people in his community. It gave him the opportunity to practice and develop his social skills through regular interactions with a group of people. The voluntary position broadened his social support network and exposed him to community resources and activities. Liam expressed he could rely on and access support from his associates made through volunteering. Additionally, volunteering provided a routine for him and gave him a sense of purpose. Associations with colleagues formed through volunteering or employment may provide bridges to other opportunities or resources for adults with ASD. However, many adults with ASD reported inadequate opportunities and social encounters available to them within the community.

Limited or absent bridging social networks expressed by adults with ASD narrowed their radius of social connections and access to resources. Consequently, most adults with ASD did not experience ‘getting ahead’. Social and communication difficulties can prevent adults with ASD from participating in community activities and functioning in a job suited to their skills and knowledge. Most adults with ASD did not seem to have the leverage of access to opportunities or resources bridging relationships can provide, including within employment. Conversely, bridging networks are bidirectional and limited inclusion and investment in social relationships with adults with ASD by work colleagues and community members diminished the range of diversity that adults with ASD may provide and contribute to greater outcomes.

### Cyber relationships

Technology is revolutionising the way people connect and may provide new networks for information, employment or social relationships (Quan-Haase and Wellman, 2004). Liff



(2005) has described a positive empirical association between internet use and developing bridging community networks. Communication via the internet may help adults overcome social limitations or anxiety (Tyler, 2002). For an adult with ASD social networking and interactive sites can extend communication and social relationships. A number of adults with ASD reported using social media to engage with and develop social relationships. Twenty-three-year-old Harry described online chatting with ‘friends’ who shared a common interest in go-carting. Harry had never met any of these people in person but through their common interest, virtual relationships and social communication had developed. Conversely, although 65-year-old Owen stated that he communicated with his two best friends, who lived at a great distance, via telephone and email, he expressed feeling socially isolated with no face-to-face social engagement. Thus while online social communication may be sufficient for some adults with ASD, others prefer in person social contact.

However, technology also has the potential to expose vulnerable people to new risks. For some adults with ASD the use of web-based social services to meet and interact with new people heightened risks of vulnerability. They risked being drawn into unsuitable and inappropriate social interactions and situations. Some family members detailed stories where adults with ASD were taken advantage of financially and emotionally through internet connections. Norma described a number of occasions where Neal, her 47-year-old autistic son, had sent money to women he met on dating sites who had promised to marry him. Norma explained that his social naiveté and desire for a relationship placed him at risk of harm.

‘He is financially very vulnerable and easily taken advantage of. He sent money abroad to women he met over dating sites. He had joined a few of these Russian and Nigerian dating agencies. One time he wanted to go to Mauritius to bring back a wife and another time some little girl who was living with her aunt and uncle, said they were going to arrange a wedding.’

Norma, mother of Neal an adult with ASD

Limited social understanding, coupled with his desire for a relationship made Neal vulnerable to demands, intentions and promises of unscrupulous people. Neal’s access to the internet and dating sites to establish social relationships was difficult for family members to monitor and to safeguard him from abuse. Additionally, family members expressed that narrow social relationships and engagements within the community, together with poor past experiences impacted the abilities of adults with ASD to make sound social decisions. Debbie described

her brother Derek, a 29-year-old autistic man, as being repeatedly exploited by different women he met online, with damaging outcomes financially, legally and emotionally. She stated, ‘the hardest part is keeping him safe from himself, he has no concept of danger’. She explained he did not seem to learn from past experiences and he had no understanding about keeping personal information private, such as banking details and home address. The vulnerability and risk of harm of many adults with ASD was voiced by family members diligently trying to keep them safe and secure. They expressed their fear extended to the future when the safety net of family oversight and advocacy may be absent.

Moreover, formal support and social policy to ensure inclusion and accommodations for adults with ASD are initiated by hierarchical linking social networks. The next section discusses formal support accessed through linking social networks.

### **Linking social networks of adults with ASD: accessing formal support**

Relationships and resources of linking networks are connections with people in positions of power across authority gradients, such as between an employer and employee or doctor and patient. They are characterised by interactions within the social structure of society and include formal service and policy. Although a diagnostic label of ASD determined some formal support provisions, such as in education, particularly in childhood for younger adults with ASD, the accessibility and availability of formal support services in adulthood was reported as lacking. Social care and other support is based on an assessment of circumstances, needs and risks and if deemed necessary is means-tested (Pilling et al., 2012).

The diversity of needs of adults with ASD often did not fit the established levels or classifications that prescribed access to supportive services in adulthood. Family members referred to ‘hidden disabilities’ of adults with ASD, such as overwhelming anxiety, inability to complete forms, and deficiencies understanding social cues that did not meet criteria for support services but were nonetheless limiting. Although they acknowledged some people had greater need for support, frustration over inadequate formal service support to meet the needs of adults with ASD was voiced.

‘Sometimes I just wish he was a lot more severely disabled, or a lot less able than I think people would make allowances and I think more things would be in place for him.’

Debbie, sister of 29-year-old Derek an autistic adult

Debbie was referring to Derek's impaired ability to perceive and respond in socially acceptable ways to verbal and nonverbal cues and how he often misinterpreted other people's behaviour. Recently his social and communication deficits had resulted in trouble at work and with the law. He was accused of harassment at work and let go from his position. Debbie expressed that had Derek's disabilities been recognised, with support provided in the workplace, negative outcomes may have been avoided.

However, parents also reported that some adults with ASD with greater disabilities also experienced difficulty accessing formal support. Twenty-two-year-old Bruce had learning disabilities, speech difficulty, and ASD. He received a personal budget, disability living allowance and educational support. His mother Betty described he could be very demanding and 'violent if things are mismanaged and not organised'. She explained ongoing struggles and frustrations over formal support provision and described policies for adults with ASD as poor.

'What is hard for me is poor policies in place, poor strategic planning, and the lack of a long term vision. There is absolutely no reason that his life [Bruce] should be crisis driven. It's unacceptable, but it needs to have clear, long-term planning which respects him and his right to live an ordinary life.'

Betty, mother of 22-year-old Bruce an autistic adult

Betty was concerned that only when circumstances would reach a crisis point for Bruce would decisions be made for him to receive the services that he needed to maintain his safety and wellbeing. Moreover, decisions made in a crisis situation may be limited and not optimum. She believed that through forward thinking and planning, crisis driven reactions could be avoided. Betty drew comparisons between opportunities available to Brian, her younger neuro-typical son, and Bruce her son with ASD. She expressed for Bruce to 'live an ordinary life', ethically and morally he had to be entitled to equal opportunities. She described using her younger son as a 'bench mark'; if he could do something she believed parallel opportunities with support provided should be available to Bruce.

'My aspirations for Brian are the same for Bruce; which means paid employment, continuing education, adequate housing and access to good health care.'

Betty, mother of 22-year-old Bruce and 21-year-old Brian

Bruce needed daily support, which was primarily provided by his mother. Moreover, Betty described organising and advocating for support for Bruce was a 'full-time job' and she was concerned about the continuation of individual personalised support for Bruce in the future when she was not able to intervene on his behalf. She stated, 'Bruce needed the right environment, with the right amount and timing of support to maintain his wellbeing'.

#### **Linking into health and social care services**

Many family members expressed that adults with ASD could not identify and/or verbalise their needs, although they had proficient language skills. Gregory, 24-year-old George's brother stated, 'He can't communicate his needs because he doesn't know what he needs'. Additionally, adults with ASD described difficulty understanding and expressing their needs. At 29 years of age Derek did not want his mother to accompany him to a doctor's visit when he had a minor health problem. However, his inability to express his health need necessitated a second appointment accompanied by his mother to obtain the medical support required.

'Even though he had a problem he just sat there and smiled and never got to the bottom of why he was there. I had to make another appointment and go with him. He doesn't have the communication skills and I worry that things like blood pressure and cholesterol, you know routine things could cause him problems later on because he would never ask for a blood test or to have his blood pressure done.'

Diana, 72-year-old mother of Derek

Mothers expressed greater awareness, patience and time was needed by medical professionals to meet the health care needs of adults with ASD. Additionally, adults with ASD reported great difficulty accessing information by telephone and completing forms which may limit information or ability to access essential resources.

#### **Linking into employment opportunities**

Many adults with ASD received financial disability support but desired to have meaningful employment. Family members and adults with ASD expressed opportunities and social support for successful employment was missing.

'When he has gone for a job interview in the past because he has no other access to support, I have got to go with him and I don't think they have given him full credit for what he is able to do because his Mum is there, but he can't not have somebody there.'

Grace, mother of 24-year-old George an autistic adult

George had never been employed. Grace expressed that his self-esteem would benefit from fulfilling an adult role of employment and contributing to the community, something he would be capable of with the right type and amount of support. Without effective support to acquire and maintain a job most adults with ASD remained unemployed.

Moreover, individual support and resources beneficial for adults with ASD through linking social networks may have collective gains for society as well. For example, Peter, Paul's father, described the benefits Paul and his work colleagues gained through support provided by his manager. Paul is employed as a cemetery landscape worker for his borough.

‘Recognition in Paul's case by his director, the senior manager at his work made a lot of difference. He instructs the line manager and they see him [Paul] as a member who needs help. He sent the line manager on a course for mental health and how people with mental health problems cope with employment and what support they need and had ASD awareness training for the manual labourers he [Paul] works with.’

Peter, father of 38-year-old Paul

Peter expressed, ‘Paul feels valued’, as a team member with support and understanding provided by his managers and colleagues. The senior manager distinguished not only Paul's support needs, but the educational support his work colleagues needed. In a position of command, he influenced the provision of resources of support and education benefitting Paul and his co-workers. However, benefits afforded through linking social networks were not evident in the lives of most adults with ASD. Moreover, social and communication limitations, as well as the criteria for access to formal services in England may compound the difficulty for adults with ASD to acquire essential services and support.

## Chapter summary

In this chapter, social networks of bonding, bridging and linking provided an investigative structure to explore and conceptualise the social relationships and resources that are available and accessible to adults with ASD. The findings underscored the social network as a crucial component in meeting current and future support needs and wellbeing of adults with ASD. The three layer social network identified in this analysis helped explore which formal and informal support and resources adults with autism currently have and need. Findings emphasised the stability and continuity of parental relationships and support with most adults with ASD having strong, if limited, bonding networks. This accentuated the linked lives of

parents and their adult children with ASD across the life course. However, analysis suggested that close family bonding networks of many adults with ASD may be diminished or absent in the future with greater need for formal support. Siblings may not be able to provide the same level of relationship and resources for a brother or sister with ASD after the death of their parents.

Behavioural, social and communication deficits of adults with ASD contributed to their limited bridging and linking networks. Findings also suggested currently most bridging and linking social networks do not adequately recognise, accommodate, understand, or appropriately support the needs of autistic adults. There is a need to build a fuller understanding of the pathways through which social resources are available and accessed for adults with ASD to ensure continuity of wellbeing as needs and social networks change.

Understanding the social networks of adults with ASD may provide a framework to explore how issues of social relationships, daily routines, structure, opportunities and support impact daily living. It may enable service users and providers to create person-centred goals that address prioritised concerns.

A limitation of applying the framework of social capital networks to describe the relationship and resource patterns of adults with ASD is over simplicity of individuals, relationships, and resources. Not all relationships are equivalent nor are the resources that they may provide. Additionally, the diverse range of individual social abilities and needs of adults with ASD, as well as community awareness and resources for ASD are not adequately represented by social networks. However, findings may help inform policy formulation in regards to greater inclusion and accommodation of adults with ASD and improvement of awareness and access to supportive resources. The next chapter addresses the general welfare needs of adults with ASD identified through interview analyses.

## **Chapter 9: General Welfare: welfare support needs and future support plans for adults with ASD**

This third and final qualitative chapter describes the current and anticipated future social welfare needs of adults with ASD, and addresses the research aim to explore whether and how families plan for future support. Social welfare needs were quantitatively defined in ten domains of the CANDID encompassing financial and personal safety, and wellbeing. Two key areas of high social welfare support need identified on the CANDID: money budgeting and exploitation risk featured prominently, without prompting, in qualitative interviews and are presented in this chapter. A support need unique to adulthood, money management was consistently reported in quantitative and qualitative data in both age groups of adults with ASD. Yet, despite its significance to the everyday lives of participants, scant research exists in this area (Sperry and Mesibov, 2005). Moreover, qualitative analysis of money management challenges and adverse experiences of adults with ASD revealed underlying family concerns for exploitation and adequate future support. This and more general exploitation risks for adults with ASD, are described and discussed in this chapter.

Changes in technologies (Trilling and Fadel, 2009) and political economies (Flint, 2003) in the 21<sup>st</sup> century demand a new mix of financial management skills and consumer competencies. Individual financial literacy to monitor and manage money, and the ability to be an active, informed, and experienced consumer is greater than ever (Atkinson et al., 2007). Technology, specifically the Internet, has changed the way that people interact, communicate, bank and consume information, services and products (Quan-Haase and Wellman, 2004). Technological capabilities and features of the Internet and World Wide Web have prompted the need for savvy, informed users and consumers (Quan-Haase and Wellman, 2004). Additionally, a new set of risks is associated with technological advances with concerns for misinformation, safety and security (Miyazaki and Fernandez, 2000, Whitman, 2003). For example, the disclosure of private and personal information given in making online purchases or social communication may be compromised or subject to theft, fraud or abuse. Adults with ASD who are more vulnerable and trusting, and less able to make critical decisions, may be at risk of being exploited or harmed financially, emotionally or physically. Financial abuse can take many forms, including persuading, tricking, or threatening the individual out of money, property, or possessions in person or over the

telephone or computer, but technology may create added risks with the potential of private information being compromised and abused (Whitman, 2003).

There is a growing appreciation that financial exploitation and abuse of older adults in general, without autism, is an increasing issue (Beach et al., 2010). Research has characterised financial victims as typically old or oldest-old females with socio-emotional vulnerabilities including social isolation, being unmarried, low social support and often invisible to social service providers (Acierno et al., 2010, Bond Jr et al., 2000). Similarly, adults with ASD may experience socio-emotional vulnerabilities as they age. Moreover, challenges with social skills and money management may place them at risk of financial abuse or exploitation. However, there is a paucity of research on financial management and security for adults with ASD. Findings from this research begin to fill this gap raising awareness of the money management support and safeguarding needs of adults with ASD.

Social services are at the forefront of the continued neoliberal transformation of public services and the welfare state in the UK (Whitfield, 2012). Neoliberalism is a political economic ideology based on promoting "rational self-interest" through policies such as privatisation and reductions in government spending in order to enhance the role of the private sector in the economy (Martinez and Garcia, 1997). The reasoning is this promotes an increase in user choice and diversity of service providers. Local authorities have systematically reduced in-house provision of social care through contracts with private service providers (Harlock, 2014). Social support services in the UK are becoming more consumer driven with increased personal responsibility for choosing and managing support services through personalised budgets based on need (Netten et al., 2012). Individual welfare of those in need of support services may be dependent upon their ability to be an active, informed and experienced consumer seeking out the best, economical, and effective support from privatised services (Scammell, 2000). Accurate recognition and assessment of the welfare needs of adults with ASD is essential to effective support provision (McCaslin and Tibeziinda, 1997). Understanding how abilities and needs are conceptualised and identified by adults with ASD, family members, and society at large is a central factor in designing measures taken to meet them. Under or over estimating competencies and support needs of adults with ASD may impact their wellbeing and safety (Robertson, 2009).



However, a compelling theme of contested perspectives in regards to the perceived abilities and support needs of adults with ASD developed through text analysis in this study. Parents, siblings and partners often held divergent views to those of adults with ASD. Zetlin and colleagues (1985) described contested perspectives between parents and adult children with mild intellectual disabilities, with adult children expressing parental interference, imposed restrictions, over protectiveness and reluctance to relinquish decision-making. However, little research has reported contested family perspectives in autism and none specifically could be found in regards to the ability and support needs of adults with ASD, despite extensive searching. This theme helped to emphasise the research question (iv), what are the patterns of relationships, and interactions between family members of adults with ASD?

Deficits in executive functioning, a broad category of cognitive skills that includes the ability to plan, organise, and complete tasks (Kenworthy et al., 2008, Ozonoff, 1997) may account for some of the intellectual and functional discrepancies reported by, and about adults with ASD. Characteristics and skills associated with executive function include: inhibition, planning, organising, initiation, flexible thinking, and processing information (Anderson, 2002). Executive function is diverse, with related and overlapping skills involved in successful management of routine everyday activities. Research has identified both executive function deficits (Hill, 2004) and decision-making difficulties (Luke et al., 2012) in adults with ASD. Some reported difficulties, actions and areas of welfare need of adults with ASD described and discussed may be associated with weak executive function. Yet, specifically how deficiencies in executive function may influence the support needs of adults with ASD currently, and for the future, has not been explored.

Although research attention and resources have been directed at supporting adolescents with autism making the transition to adulthood (Hendricks and Wehman, 2009, Taylor and Seltzer, 2011, Wehman et al., 2009), local authorities are not required to provide support for adults with ASD transitioning out of parental support to independent living. To date, little research has focused on this transition. Independent living represents a major life course transition and is considered a normative developmental progression in adulthood (Holdsworth and Morgan, 2005). Independent living is defined as having the freedom and dignity to make personal choices, and have control at home, work, and in the community

(Morris, 2003). It does not necessarily mean living alone or managing without support (Fine and Glendinning, 2005).

Participants in this study described a wide range of support adults with ASD required to enable decision-making, choices, and the achievement of independent living. Moreover, most adults with ASD were not living independently and family members acknowledged that the process of change could not be achieved in a single step. Parents, adults with ASD, siblings, and partners described a critical need for a supportive transition process. However, while families intuitively understood and expressed the importance of preparing a future support plan for adults with ASD, few had undertaken steps to create one.

The chapter begins by presenting evidence of the welfare support needs of money management and exploitation risks of adults with ASD. This responded to the qualitative research questions: (i) What are the needs of adults with ASD and (ii) how and by whom are their needs being met. Next, using welfare needs identified in the CANDID as a lens through which to describe a wider range of welfare support needs, the chapter identifies contested perspectives and presents individual discrepancies in participants' accounts of abilities and support needs of adults with ASD. For example, the need domains of accommodation, food, looking after the home, exploitation risks and safety of self, are described under a broader welfare concept of independent living. Interviewees emphasised difficulties and limited experiences in making decisions and choices among adults with ASD, and family concerns for their safety and security. This addressed research question (iii) what are the unmet needs of adults with ASD? Moreover, the thread of linked lives, a key principle of the life course theory, is evident through the continuity of intergenerational support from parents and the anticipated generational support from siblings to meet the needs of adults with ASD. Exploration of family future support plans and preparations for adults with ASD concludes this chapter. The limited plans and preparations of families for future support are described, together with the restricted availability of formal social support, and the implications of these for adults with ASD. This answered the research question (v): How are the needs of adults with ASD anticipated to be met in the future?

## **Money management and exploitation risks**

Equally represented in both age groups as a domain of high and unmet need on the CANDID, money budgeting difficulties of adults with ASD were widely expressed and described in interviews. Problems with financial literacy and skills ranged from basic understanding of the monetary value of paper money and coins, difficulty with maths and counting change, to the inability to accomplish routine tasks of bill paying, to complex tasks such as budgeting and banking. Money management difficulties expressed by and of adults with ASD included the inability to budget or pay bills, over or underspending, lending or giving money away, and difficulty understanding money.

A few adults with ASD had limited understanding of money. They had trouble understanding the value of money and difficulty counting change. Helen described how technology permitted her autistic son to perform independent activities of daily living.

‘It is a blessing that he can use his debit card, if he went into a shop with a ten pound note to buy a Mars bar [chocolate] and was given five pounds in change, he wouldn’t know it was wrong.’

Helen, mother of 23-year-old Harry

Harry had difficulty with mathematics and did not comprehend the value related to different notes and coins. A debit card enabled Harry to make purchases and provided a level of security and a degree of self-sufficiency. Presently, for Harry and other adults with ASD in this study, their spending and money was being monitored or managed by family members. A weekly or monthly amount of money was given for spending, and parents, partners or siblings managed paying bills, purchasing necessities and other financial activities. Limitations in financial understanding may impede adults with ASD from making decisions as an informed consumer and to understand the importance of their monetary actions and choices.

Inability to think ahead, or to anticipate future needs, and difficulties in prioritising and decision-making, were key concerns of family members for adults with ASD who had some control over their finances. A number of adults with ASD acknowledged having poor money management skills, and difficulty with financial planning and budgeting. William who was

employed part-time and living independently for the first time in his life having recently moved into subsidised housing, described challenges managing his finances and overspending.

I am not very good with money, but I can manage in the shops. I am crap at money budgeting because whatever I have I spend. I buy a lot online. There is no middle ground, I spend it all.'

William, a 44-year-old autistic man

Although William had insight into recognising there was a problem, he reported that he did not understand how to manage his money in an organised and structured way. Additionally, while William had difficulty with physically-based social environments and communication, the ease of online shopping facilitated his over-spending behaviour. He could not establish spending boundaries or planning for future expenses. He had a history of spending the money he had access to quickly, and would get into financial difficulties and debt. Inhibition, the ability to stop a behaviour at the appropriate time, is an executive function. Additionally, money budgeting involves the executive function ability to plan and organise current and future-oriented tasks. A deficit in executive function may have contributed to William's inability to control spending or manage budgeting his money.

Other adults with ASD had difficulty with lending and giving away money. Parents described that often the money adults with ASD had just disappeared with nothing to show for it. For example, twenty-nine-year-old Derek's mother stated, 'He just gives money away quite easily' and 21-year-old Elliot described difficulty managing his money saying, 'I lend it and spend it'. Good intentions to help others, and limited understanding and awareness of money were described as explanations for the behaviour. Mary, 41-year-old Mark's mother, explained that he did not understand the concept of credit cards, or the consequences of debt.

'He had taken out a credit card in his brother's name and he was buying friends at the pub, lending people money that he did not have.'

Mary, Mark's mother

Lending money may have been an effort on Mark's part to fit in socially and to please his friends. Without full financial understanding, awareness of spending limitations and perhaps knowledge of other people's intentions, lending money resulted in a financial debt crisis for Mark. Additionally, organisational and planning deficits may account for the 'lend it and

spend it' profile many adults with ASD described. However, in contrast to over spending and lending money, a few adults with ASD described themselves, and were described by family members, as being overly conservative and cautious with spending money. Fifty-six-year-old Liam stated he would rather do without an appliance if it broke than pay to have it repaired. This financial pattern was partly due to his restrictive spending habits and partly to the perceived stress he associated with contacting a repair service, organising a time and date, and having a stranger come into his home to assess and conduct the repair. Liam's sister described him as obsessive with saving money and very anxious about making any financial decisions.

In addition, many adults with ASD reported being unable to manage paying bills. They described difficulty processing the information on bills, organising and prioritising payments. Most had never experienced fulfilling this task and expressed insecurity about the potential of assuming it in the future post-parental or post-partner support. Forty-year-old Kate who was unemployed and continued to reside with her mother stated, 'even having the money to pay bills would be a problem, let alone the organisation to pay the bills'. Moreover, Kate described procrastination, stress and trouble meeting deadlines would compound her inability to assume responsibility for paying bills. Initiation, thinking ahead and carrying out the sequence of steps needed to complete a task fall under the umbrella of executive function. Kate's expressed difficulties of money management may be associated with weak executive function. In contrast, fifty-three-year-old Victor explained being very 'precise' managing the monthly budget, detailing specifically how much he and his partner Virginia had spent or overspent and what they had to cut back on to rectify the matter to meet his budget the following month. Victor's strong preferences for specific routines and behaviours included judicious money management.

Money appears to be a difficult concept for many adults with ASD to understand and manage with extensive consequences of incompetence, and yet it remains largely unrecognised on the evidence base of supportive services (Pellicano et al., 2014, Shattuck et al., 2012). Patterns of money spending and financial management of adults with ASD including impulsive spending, poor planning, and obsessive saving and monitoring of money may be associated with repetitive patterns of behaviour characteristic of autism, executive function deficits and

mental health comorbidities (Perry, 2009). However, unique personalities, experiences and media influences may also contribute to financial habits with learned money skills and implementing changes in spending patterns possible with effective support. Currently, informal support efforts from family members were trying to meet the financial and money management needs of adults with ASD. Formal support services may be essential when family support is unavailable.

Limited understanding of money, and the inability to manage it, may place adults with ASD at risk of harm in social and decision making situations. They may be financially exploited or pressured to make unsound transactions. Parents and siblings expressed concern about the ability of adults with ASD to keep their money safely and to protect private financial information. A number of family members described past experiences of adults with ASD sharing their bank details with strangers and acquaintances. Safeguarding adults with ASD, currently and in the future, was the highest priority expressed by family members. As children, all adults reported being bullied. As adults, exploitation risk and examples of experiences of exploitation were expressed in multiple interviews. Parents spoke of times when ‘so called friends’, sales people, and people met through internet sites, had taken advantage of adults with ASD. Adults with ASD were not able to interpret other people’s motivations and were often naively trusting. Additionally, inexperience in social situations and a desire to be accepted were described as reasons for behaviour and decisions made by adults with ASD.

‘He has a fear of being rude or impolite so he does conform or over compensate, even when he shouldn’t. If someone asked him for his bank details he would probably give it to them.’

Helen, mother of 23-year-old Harry

Helen believed Harry’s limited social and communication skills, knowledge, and experience with making decisions and choices, coupled with his ‘passive nature’, placed him at risk of being exploited. Parents described money management difficulties of adults with ASD as a huge concern for the future, and potentially a limitation to the achievement of independent living. Diana, 29 year old Derek’s mother, expressed her doubts about his capability to achieve independent living.

‘He wouldn’t be capable of living on his own, because he wouldn’t be able to keep things under control. Firstly, money and then because unless there was somebody in

the house to look after him, he is the type if he went out and met somebody he would let them move in. This is my fear of him living on his own in a flat. I think people would definitely take advantage of him.'

Diana, mother of 29-year-old Derek

Diana stated her biggest worry for Derek's future was his inability to manage his money and fear that he would be exploited. However, parents may not be entitled to make financial decisions for an adult son or daughter with autism which may place them at risk of harm. Some parents described difficulty interceding in financial matters for adult children with ASD. For example, following a negative experience where 24-year-old George gave out his banking details, his mother described being denied the ability to help him with his accounts by the bank on the basis that he was an adult. Legally, even a person with a significant developmental, cognitive, or mental health disability is permitted to make decisions on his or her own behalf in adulthood (Millar and Renzaglia, 2002). Parents no longer have the legal rights that they were entitled to throughout their child's youth (ibid). This can include financial and health decisions. A court-ordered legal guardianship in which the adult with ASD would be deemed 'incapacitated' is required for parents to continue making decisions for their adult child (Quinn, 2005).

The need for financial support and money management, particularly with reference to the future, was frequently stated by, and about adults with ASD. However, who would assume this responsibility, family or formal support services, was sometimes vague. For example, 27-year-old Frank's mother described his only sister, at the time of the interview, as 'severely mentally ill', yet in reference to future financial oversight for Frank, his mother stated, 'I think when the chips are down she may help out'. Twenty-four-year-old Albert was an only child who continued to reside with his parents; his mother perceived a negative outcome for his future without essential formal financial support.

'Is it going to take that he becomes homeless before he will receive the support and services he needs? So not only the prospect of having a job where he can live independently is restricted as far as I can see, but even if it was possible what scares me is he could not live independently.'

Ann, mother of 24-year-old Albert

Ann was referring to Albert's inability to manage his money, secure a job and other skills of daily living. Additionally, she was worried that he would be manipulated and exploited

financially if he did not receive adequate support. Moreover, the complexity of future support provision for adults with ASD was also dependent on their preferences and decisions. Debbie expressed her apprehension about her brother, Derek's willingness to permit future assistance with his affairs, particularly financial management. He currently lived with their parents and his mother regulated his spending money.

In the future, someone at some stage will have to control his finances because he is not able to do it, but I don't think that he would let me. I think that he would fight me all the way and stop me from having any control.

Debbie, 29-year-old Derek's older sister

Ethically, practically and legally it is difficult for a sibling and parent to assume responsibility and control of some affairs of a brother or sister with ASD without their consent or legal guardianship, such as making financial and medical decisions. Debbie explained Derek had a complex personality, which from her perspective included a combination of naïveté and over confidence. She stated he resented being told what to do but lacked experience and judgement in making decisions. She anticipated future contention regarding her efforts to help manage his money and worried for his safety. A few adults with ASD, including Derek, expressed not wanting, or needing their sibling to assume future responsibility, or to provide a support role. Adults with ASD may have complex needs, cognitive and/or communication requirements that can present challenges for informal and formal support providers, particularly in managing risk and safety. Adults with ASD should be active participants in planning and obtaining the supports they feel will best meet their needs and goals. Their choices and preferences should be respected (NICE, 2016). This can be difficult for a family member who believes they are acting in the best interest of the adult with ASD. This section underscored how an unmet need in the seemingly inconspicuous area of money management may significantly impact the safety and wellbeing of an adult with ASD. Fundamental to providing support formally or informally for an adult with ASD is an understanding of what support needs are required. Family members may have different opinions, beliefs, and goals about an individual's support needs, as described in the next section.

### **Contested family perspectives**

Individuals with ASD have multiple abilities and disabilities across a wide range of social and functional areas of daily living (Saulnier and Klin, 2007). An individual's abilities and



disabilities determine their support needs. Renty and Roeyers (2006) identified the importance of a substantial needs assessment and effective support for quality of life among adults with ASD. How the needs of an adult with ASD are defined and identified is relevant to how they are met. As such, an accurate assessment of need may depend on what is assessed, by whom and with whom.

Social services' eligibility threshold for adults with care and support needs in the UK is based on identifying how a person's needs affect their ability to achieve relevant outcomes, and how this impacts on their wellbeing (Department of Health, 2003). Separating ability from need for adults with ASD can be challenging. An adult with ASD may find a needs assessment confusing for a number of reasons including: difficulty understanding the questions, lack of self-awareness, or the ability to express their needs, they may conceal or minimise their difficulties, or have had poor past experiences with services (Saeki and Powell, 2008). In addition, family members who provide the majority of support for adults with ASD may mediate the outside world and compensate for the adult's difficulties.

However, findings in this study revealed conflicting perceptions of the abilities and support needs of adults with ASD reported by adults themselves and by family members. In comparison with the perspectives of other family members adults with ASD reported more abilities and fewer needs. While parents and siblings expressed that the individual choices and preferences of adults with ASD that enhance their personal independence and autonomy must be respected, they emphasised that these choices and preferences must be balanced with maintaining their safety and dignity. Although contested family perspectives were not limited to the category of welfare needs, they were most evident in the analysis of data pertaining to its domain. Therefore, through the lens of welfare needs, broader contested family perspectives of abilities in skills of daily living and support needs of adults with ASD are presented. While not implying one family perspective is better or more 'truthful' than another, this section highlights discrepancies between the expressed abilities and support needs of adults with ASD which may require consideration for how needs are assessed, and support provided.

## Contested perspectives of need between the quantitative and qualitative reports of adults with ASD

Discrepancies of need were noted between what an adult with ASD reported on the quantitative questionnaire and what support needs were stated in their qualitative interview. Quantitative and qualitative interviews were not conducted at the same time, with an interval time varying from a few months, up to a year. However, it is unlikely needs would change significantly over that time. The CANDID is an objective assessment of need in 25 areas of wellbeing that includes closed ended questions with an established rating scale. While the CANDID addressed current support needs, qualitative interviews asked subjective open ended questions relevant to current and future support needs.

Some disparities were evident in what an adult with ASD reported as current needs for support on the CANDID and their needs expressed in qualitative interviews. For example, although adults with ASD itemised numerous current support needs across a number of domains on the structured quantitative questionnaire, in responding to qualitative interview questions pertaining to their current and future support needs many expressed having few or no needs. This may highlight differences in responding to question formats, one being closed ended and the other open, as well as difficulty with planning and projecting what may be needed in the future. The quantitative list of areas of need may have facilitated adults with ASD in identifying their specific support needs. The open ended questions may have been more challenging for them to answer. Some adults with ASD expressed not being able to identify their own needs and wants, or to envision what alternatives there may be to the current situation.

‘I find it quite difficult to tell you what I need. If you had a menu I could choose from it and tell you but I don’t have any imagination to tell you what I need. I can’t tell you if there is anything missing because I don’t know’.

William, a 44-year-old autistic man

William was not able to know or predict what he needed, or may need, in the future and he stated it made him anxious to think about it, so he tended not to. However, he said that an itemised format would help him identify his needs and if he would require support meeting them. Additionally, difficulty with social interactions compounded the complexity for him of asking for help or support. William explained he received housing support and disability living allowance but no other help or support. Difficulty asking for support, and/or ability to

negotiate effectively with the service systems, and to take and act on advice, may contribute to adults with ASD being at risk of not having their needs met.

Unintentionally, the demeanour of the researcher or the way in which the questions were asked may have resulted in response bias. In addition, the desire of the adults with ASD to provide a socially suitable response may have affected their answers. In the face-to-face interviews the adults with ASD may have felt more pressure to minimise their needs providing biased responses. In general, in the qualitative interviews, adults with ASD reported having few needs of support for the future. However, many adults with ASD may have had an unclear perception of their support needs, as at the time of the interview most resided with parents or partners who ensured and regulated their living environment and attended to many of their support needs. Imagining how they would manage, and what support they may need, in the future when family support may change could have been difficult to envision. Moreover, reported perceptions of abilities and support needs of adults with ASD varied between adults with ASD and their family members.

#### **Contested perspectives with family members**

Even though an adult with ASD may perceive they would be able to physically do, or are able to intellectually understand what is required, they may be practically inhibited to carry out the necessary steps or social interactions to accomplish specific tasks in everyday life. No clear age-related pattern or common characteristics were identified in adults with ASD in reference to perceived abilities, anticipation of independent living and contested family perspectives. However, in general younger adults with ASD appeared more confident in their capabilities and their parents and siblings expressed a very different point of view, than older adults and their family members. Older adults with ASD who had never lived outside the parental home were noticeably less confident and more fearful about their ability to live independently in the future. They commonly expressed concerns about loneliness and mental illness in the future post-parental support. Yet, many of their family members held a more positive view of their proficiencies for independent living.

Younger aged adults with ASD frequently described their current and perceived future capabilities as higher than perceptions reported by other family members. However, some

incongruities were noted between what an adult with ASD stated he/she 'could' do and what he/she was 'actually' doing. This was particularly noticeable in discussions about abilities of daily living, such as money management, cooking and doing laundry. A number of adults with ASD explained that although currently they could not or did not perform an activity, they believed they would be capable of accomplishing it in the future. For example, 24-year-old Albert, an autistic adult and only child, explained that he had 'not learned to manage money very well', he did not know about his bank accounts or how to pay bills. Yet, when asked if he would be able to manage his own finances in the future, he confidently replied, 'I think that when the situation or the circumstance calls for it, I will learn to do it'. Albert's statement underscored that he was living in the moment, with little planning or forward thinking. As he continued to live with, and was financially supported by, his parents it may have been difficult for him to anticipate needing these skills in the future or the possible consequences of limited financial ability. His mother presented a somewhat different perspective. She described her efforts to teach him financial responsibility and other daily living skills when he turned 15 years of age.

'[I said to him,] in 365 days you will be 16 and can function as an adult. So we have 365 days that I can teach you, guide you through essential skills so that by the time you are 16 you'll be ready. But no, even now there is not an iota of interest.'

Ann, mother of 24-year-old Albert

Ann explained, and Albert acknowledged, that he lacked other skills of daily living such as cooking and doing the laundry. She described her frustration at both Albert's disinterest in learning, and difficulty retaining, what she perceived as essential life skills. When Albert went away to college for a 6 month fine arts course, his limited skills became an evident problem. His parents continued to manage his finances, paying his rent, food bills and tuition but Anne stated, 'I saw a person headed towards homelessness'. Albert was unable to organise his time, his self-care or plan his meals. Albert did not maintain normal sleeping and waking hours often staying up until the early morning hours and sleeping until the late afternoon. His attendance at school was not regular and he refused to use the kitchen or the bathroom at his residence. His perceived ability to learn to manage and accomplish financial and daily living skills when the situation required it, differed from both his own past personal experience and his mother's perspective of his ability.

Some parents expressed what they believed to be their child's 'unrealistic expectations' and 'inflated abilities' of adult children with ASD. For example, Fiona, 27-year-old Frank's mother stated, 'He is very unrealistic. He has high ideals and thinks he can do all sorts of things. His ability is far beneath what his ideals are'. Whether parents underestimate, or adults with ASD overestimate their ability, may be hard to determine but could have ramifications for what and how support is provided in the future. A number of family members expressed concerns about the risks of physical and social isolation or harm of adults with ASD in the future if support needs were unmet. Parents, with their perceptions of intimate knowledge of the abilities and needs of their adult children with ASD, often expressed concerns about their abilities in regards to safety and wellbeing. However, although concerns about safety are real and may be well-founded, they may also have led parents to overprotect their adult children with ASD and to restrict their ability to make their own choices and decisions. For example, Betty, 21-year-old Bruce's mother stated, 'it is the Peter Pan thing. They [adults with ASD] have never had a life, never made their own decisions'. Helen, 23-year-old Harry's mother expressed on the one hand, her worry about what will happen in the future, 'if we don't push him out and let him have exposure to the world' and on the other, how she needed to, 'shield him from the news because he has difficulty separating reality and imagination'. Both mothers described being very protective of their adult sons and expressed great concern about how they would manage in the future when they could not provide the buffer between them and the outside world. Yet the achievement of independent living was an expressed goal of many adults with ASD and their family members.

### **Independent living**

For some adults with ASD the timing of independent living occurred, or was anticipated to occur, in middle age and beyond, often when parents were unable to continue providing support. While a third of adults with ASD were living independently, alone or with a partner, fourteen of twenty-one had not made the transition to independent living and continued to live with their parents. Most who continued to live with their parents expressed the desire and expectation of achieving independent living in the future. Likewise, most parents described some level of independent living as a future goal for adult children with ASD. Yet, contested perceptions of the capability and support needs essential for adults with ASD to achieve independent living were distinguished between reports from adults with ASD and

their family members. Parents explained that adults with ASD had no reference about, and limited awareness of, what independent living would entail and some expressed doubts about their capacity to achieve it without formal support services and social welfare benefits.

Frequently, younger adults with ASD (18-29 years of age) described their expectations and abilities of independent living to be higher and support needs lower, than what family members perceived them to be. Some expressed a desire to achieve independent living outside of the parental home in the future and reported anticipating minor adjustments and little support necessary. For example, 29-year-old Derek explained that he would like to live with 'other people' and that he 'might' need some help initially with cooking and laundry but he was confident that he could do it and would be fine. Derek's image of independent living was un-conceptualised and seemed more imagined than thought out. Other younger aged adults (18-29 years of age) also described 'imagined' futures living independently, either alone or with others that were a sharp contrast to their dominant current situation being unemployed and living at home with informal support for activities of daily living. Derek described the support his parents provided for him as, 'they help with my money, with my finances, living here, cooking, and washing'. His mother, Diana and sister, Debbie reported a different perspective, explaining that he does not understand his limitations and 'imagines he is more capable than he is'. Diana described the level of financial and practical support that she and her husband currently provided for Derek and, drawing on Derek's past experiences with financial and legal indiscretions, stated that she did not believe he would be able to live independently. Debbie explained he would need a high level of support but worried he would 'fall through the cracks' in service provision. She said, 'where he is, the level he is, he does not get the support he needs'. Frequently, family members expressed the inaccessibility and unavailability of adequate formal support provisions for adults with ASD. This matter is addressed in greater detail later in the chapter. Current support levels, limited communication and skills of daily living may suggest Derek and others expressing similar understanding of their future, would require more support to enable them to adjust to independent living than was expressed. Deficits in executive function may make it difficult for adults with ASD to anticipate the future, inevitable changes that may occur and the tasks with which they may need support.

Older adults with ASD (30+ years of age) who continued to reside with parents described living independently while remaining in the parental home after their parents' future death. For example, at the age of 41, Mark had never lived outside his parents' home and did not anticipate doing so. He reported he would need emotional, financial and functional support to enable him to remain living there after the loss of support his parents currently provided.

'I don't think that I will be safe in a flat on my own. I could not control the rent. I'd be lonely. I would start to go into the bit of not washing, never getting out of bed'.

Mark, a 41-year-old autistic man

While Mark did not believe he was able to live alone, he did make personal choices and decisions in other areas of his life including daily activities, clothing and food preferences and personal habits. However, his brother implied he could, and should be, doing more to acquire greater independent living skills in preparation for the future when his parents would no longer be able to support him.

Has he bothered to cook? No. Can he cook? No. Has he shown an interest? No. Should he? Yes. He needs the skills and ability to do that. He is 41; I think he should learn to cook. Mum cooks every day. I would say it to anyone else and so I say it to him. Don't let your Mum do it; cook and wash for yourself.

Matthew, 38-year-old brother of Mark

Matthew described Mark as lacking the initiative and motivation to learn to accomplish skills of daily living and contested his ability to do so. A clear contradiction existed between Mark's perceptions of his abilities, and his brother's perception of what he should be capable of, given his age. Discrepancies between chronological age and functional capacity presented a conflicting role expectation. Moreover, this contested perspective may become a problem in the future as Matthew anticipates assuming support for Mark when their parents are no longer alive or unable to continue supporting him. Mark had only recently received a diagnosis of autism at the time of the interview and perhaps Matthew did not associate his brother's limitations in daily living skills with his autism. Others expressions of laziness and inconsistency on the part of the adult with ASD may also have reflected family misunderstanding of ASD and the capabilities of adults with ASD. However, for Mark and many other adults with ASD limited life skills narrowed the options and choices available to them including independent living without support.

A small number of family members, from both age groups, envisioned an easier transition to independent living compared with that expected by adults with ASD. For example, Liam, at 56 years of age had lived continuously with his mother and anticipated making the transition to living independently when she dies. He described that he would need financial and emotional support from his sister. Additionally, he stated he worried about when things go wrong and his ability to handle the 'unpredictability of things'. He made reference to an appliance not working and his inability to take the steps necessary to get it repaired. Liam expressed having difficulty making decisions, planning and organising. Limited executive function may be associated with Liam's diminished sequencing ability. For many adults with ASD high anxiety was described as debilitating. His sister acknowledged how much their mother currently did to support Liam but expressed confidence that he could 'rise to the occasion' and be capable of taking care of himself in the future without his mother. Liam had received the diagnosis of autism in childhood which may have helped his family members' understanding, acceptance and adjustments to his autism across the life course and given them greater assurance in his ability to make the transition to independent living. However, Liam was less confident and worried about the future and living alone.

No siblings or adults with ASD commented on the likely emotional experience of losing a parent's support and the impact it may have. Although this was not an area of questioning, the loss of the parent's multifaceted roles, such as provider, emotional supporter, companion, teacher and advocate, which many were currently furnishing for adult children with ASD, may have been too difficult for them to imagine or too personal to discuss. A few parents expressed concern for the mental wellbeing of, and advocacy for, adult children with ASD after their death, however, foremost were concerns for their adequate financial and instrumental support. The lifelong financial, housing, instrumental and social support that these parents provided for their adult children with ASD highlights the linked lives principle of the life course perspective and the importance of family to the security and well-being of many adults with ASD.

Contested perceptions of capability and support need were also expressed of adults with ASD who were living independently at the time of the interview. Seven of twenty-one adults with ASD had achieved a level of independence and self-sufficiency with relatively normative



accomplishments of managing their own flats, being married or cohabiting. For example, at 47 years of age Neal (now aged 48) had moved away from home for the first time to a supported living accommodation. He stated he was adjusting to changes and expressed that he did not think he needed the level of support staff were providing. His sister held a different perspective. She felt support staff at the facility were not overseeing him enough or adequately encouraging his engagement in social activities with other residents.

‘He always goes overboard in his abilities. He is vulnerable yet he will tell you he is not. He’s also vulnerable in cooking. He doesn’t know what he is doing. He has already had two fires. He blew up the first microwave in short order and he set the toaster on fire. When they [staff] could smell something burning they went in there and the microwave was on fire. They said turn it off and he did and then he went to pick it up, so they had to yell at him to stop. He panics in an emergency’.

Nancy sister of 47-year-old Neal

Nancy reported she believed Neal inflated his abilities out of fear of seeming incompetent or unknowledgeable. She stated he had difficulty knowing how to ask for help and limited insight of knowing when he needed help. She worried his overconfidence, difficulties and behaviours placed him at risk of harm. Moreover, Nancy described heightened stress associated with a crisis situation incapacitated Neal’s judgement and could affect his personal safety. The highest priority expressed by family members, for an adult with ASD’s achievement of independent living, was the support they would need to maintain their safety and wellbeing.

### **Transition to independent living and formal support services**

Many family members expressed the changes required in the lives of adults with ASD to achieve independent living would require a transition process incorporated over time and with the supportive influence of family. They described a variety of possible progressions and the individual support that was required at each stage as adaptation to changes in life circumstances would be acquired. The transition was envisaged as a slow process over an extended period of time. For example, Ann, 24-year-old Albert’s mother, stated, ‘first it will be one night, then one week and may take 3 years’ time to complete’. Essential to all transition scenarios presented was the necessity that they be undertaken while parents were able to support the process. For example, 23-year-old Harry’s mother explained, ‘he needs to take the steps to become independent while we are young enough to make sure he is on top of

things'. Moreover, parents explained that transition planning to independent living had to be individualised based on needs not age as many adults with ASD faced this process at midlife or older. Most of the older adults with ASD who continued to reside with their parents anticipated staying in the family home after their death. Some families had identified siblings as key support in the transition process and others suggested formal services would be required. However, all parents expressed that no concrete preparations for the transition process of adults with ASD to independent living had been initiated. Additionally, many parents expressed anger and frustration at what they described as insufficient services and support available for adults with ASD to make this transition.

#### Practice lags behind policy

Often adults with ASD or their family members acknowledged that they were receiving some welfare support, primarily financial, but described needing, or anticipating the need for, more instrumental support. Frustration about government support for adults with ASD was particularly evident in the statements of many parents whose adult children continued to reside with them and for whom they continued to provide the majority of support. For example, Betty, 22-year-old Bruce's mother, expressed what she perceived as a lack of strategy and forward planning by social services. She described a response she received in regards to a housing support request for Bruce.

They came back to me and said that he is adequately housed with you, he has got adequate housing. I replied, "I refuse to intentionally make him homeless, to compromise him or our dignity to suit your needs. I will not be crisis driven, you plan it".'

Betty, mother of 22-year-old Bruce

Betty and other parents expressed concerns about a future crisis being the entry point to support services for their adult children with ASD when they are not able to support them or advocate on their behalf. Homelessness, mental illness and trouble with the law were future crises family members envisioned for adults with ASD without adequate and appropriate support to meet their individual needs. For example, Mary, 41-year-old Mark's mother, described what she thought was the attitude of service providers about adults with ASD. She stated, 'they've [adults with ASD] grown up and they've survived this long, so they don't need our [service providers] help'. Mary felt that both adults with ASD and the families who provided for their welfare go unnoticed and unsupported by social support systems. Some

parents contrasted the support they perceived children with ASD currently receive with the support available to adults.

‘What I see is that it is all focused on school children [with autism]. Adults [with autism] don’t get enough attention. Social services have a care plan for him, but it is just a piece of paper and they don’t do very much. They have a lovely statement about their standards but when you experience it, or check it out, it does not happen.’

Peter, father of 38-year-old Paul

Family members described a gap between policy standards and statements for support and what adults with ASD actually received. Peter also felt parents of adults with ASD were as silent and as invisible as their adult children with ASD. He expressed that parents of children with ASD were ‘much more vocal’, that society was more sensitive to, and aware of, children with ASD and as a result they received more services and support than adults. A number of parents and siblings expressed the criteria for support services did not adequately recognise the support needs and vulnerability of adults with ASD. Some regrettably stated they wished their family member was more severely autistic which would ensure they received adequate support services. Parents, partners and siblings expressed that often society viewed adults with ASD as someone who ‘appears’ to be intellectually able to accomplish much more than they do, or can do, and they do not receive adequate accommodations or social support to meet their needs. Moreover, they described how vulnerable family members with autism were and could be without appropriate support. These findings seem contrary to the guidance that currently underpins policy and practice relating to the assessment of and support for adults with ASD and their carers described in Chapter 3. However, research has identified a lag time between the announcement of policies and the observed results (The Health Foundation, 2014). Limited service provision was reported as a heightened concern for the future when current family support may be diminished. However, parents may have been unaware of policy guidelines and how to access support to which they and their adult children with ASD may be entitled. Moreover, few families reported contingency plans for the future should support services be unavailable or inaccessible for adults with ASD.

### **Future support plans for adults with ASD**

Family future support planning and preparations were discussed in interviews with parents, adults with ASD, their siblings and partners. Specifically, interviews explored whether 1) elements of a plan were in place, and 2) whether or not these plans had been discussed overtly,

and if so, with whom. What would happen to their adult son or daughter with autism after they were gone was a frequently expressed worry by many parents. Uncertainty about how would they live and be supported in their daily lives was described as a constant concern. Most adults with ASD reported the need for some future support post-parental or post-partner's current provisions, with a wide range of needs and quantity of support identified. However, few parents reported having initiated financial procedures, living arrangements or instrumental support plans for adult children with ASD. Almost all siblings expressed the assumption of some level of responsibility and support for a brother or sister with ASD beyond the lifetime or capability of parents. No distinct pattern of planning for future support was distinguished by age group of adults with ASD (18-29 or 30+ years of age) with most families having no developed plans.

#### **Future plans from the parent's perspective**

Most parents reported future support for an adult child with ASD was something they constantly thought about, but few had developed or discussed a plan with other family members. Present priorities and demands, not knowing where or how to begin, the enormity of the task, limited information and 'paralysing fear' were cited as explanations for limited preparations and planning for future support. These parents, who have managed and controlled the support and welfare of adult children with ASD for years, expressed feeling helpless to prepare for a future that seems out of their control.

Although no distinct pattern of planning for future support of adults with ASD by age group was distinguished, two of sixteen parents who identified having established future plans were mothers of autistic adults in the 30+ age group. Kay was divorced and Lucy widowed, both were over the age of 70 years (71 and 91 respectively) and continued to reside with their adult child with autism. These parents described being self-reliant, having received very little support in raising their adult children with ASD. Lucy's son Liam (56 years of age) received a diagnosis of autism in childhood, but she stated, 'We never asked for any social support'. Lucy expressed that she would not live forever and needed to ensure that Liam would be supported after she died. Her future plans for her son included arrangements of financial, accommodation and instrumental support. Liam would remain living in the home he currently shared with his mother. Lucy had made financial arrangements with her accountant

and lawyer and had changed all of the utility bills to Liam's name. Liam's only sister, who was 7 years his senior (63 years old), would assume his daily support needs including meal preparations, laundry and bill payments.

Kay's daughter Kate (40 years of age) had recently received a diagnosis of ASD in adulthood. Kate described difficulty completing the paperwork to receive disability support. Kay's future plans for Kate involved financial planning and securing her accommodation but did not include her need for help with some activities of daily living, such as bill paying and money management.

Financially she will be able to continue to live here. So she will have stability but she will have to adapt to doing things on her own. She has organisation problems and is not good at problem solving so she will need some support with some daily activities. Who will help her I don't know.

Kay, 40 year old Kate's mother

Kay implied Kate would need formal support services to help her manage paperwork, bill paying and help with organisation. Kay had a hoarding condition, mental illness and other physical ailments and sensitivities. Although both mothers reported being healthy, a future without their advocacy and support may have been perceived as more imminent.

Nineteen families had not imitated any preparations or plans for the future support of their family member with ASD. Some younger age group parents expressed the need to plan for the future support of their autistic adult son or daughter was a distant task, with more pressing present challenges taking precedence. Other parents stated not knowing where to begin and a few family members identified that future support plans were unnecessary.

The linked lives of parents and their adult children have endured societal and family changes, often with parents becoming sole support providers in their later years. All parents 70 years of age and older were providing sole support, either through the loss of a spouse or divorce. Some parents expressed that with advancing age they felt less capable to continue to provide support for adult children with ASD. Sixty-eight-year-old Diana, Derek's mother stated, 'I didn't feel it before, but now I am just not up to doing what I used to'. However, not all adults with ASD believed they needed to have a future plan. Future plans are discussed next from the perspective of adults with ASD.

### Future plans from the adults with ASD's perspective

Only two adults with ASD, one from each age group (18-29 and 30+ years of age), and their family members expressed that a future support plan was unrequired. Sixty-five-year-old Owen described living alone since 1978 and stated that a future support plan was unnecessary. His mother and sisters acknowledged providing emotional and some social support but felt confident he did not need a support plan. On the other hand, 23-year-old Elliot and his family members shared slightly different views of his future support need. Elliot stated, 'of course I don't think I need one' referring to a support plan and his older brother Eric endorsed this perspective reporting he believed that Elliot would be able to look after himself in the future. At the time of the interview Eric was living away from home, and Elliot was unemployed, and living with his parents who were meeting many of his support needs. Their mother expressed, 'He [Elliot] would need something, but whether he would want it, or accept it, is a different thing'. She described that establishing a future support plan and implementing it would be highly subject to Elliot's consent. Moreover, she stated that they had never discussed the topic of future support as a family.

'Now I think that maybe we should discuss it having talked with you. I think that we don't externalise things enough in our family and I think that it may actually help us to talk about it.

Emma, 23-year-old Elliot's mother

The conversation about a future support plan for an adult with ASD had not taken place in most families, but a number of parents acknowledged that the interview question had opened up a channel for that discussion to take place.

Nineteen of twenty-one adults with ASD expressed not being aware of a future support plan or being included in any family discussions about the subject. Some parents stated it was difficult for them to talk about the future with their autistic adult children and worried that it would 'unnecessarily upset' them. A number of adults with ASD described living in the moment, not worrying about the future and some reported it made them feel anxious to think about it. Twenty-seven-year-old Frank stated, 'it is too much for me and it makes me feel stressed to think about it'. Difficulty with change, uncertainty and limited forward thinking may have contributed to adults with ASD's present-focused perspective. Likewise, in most

families no discussion about future support plans for an adult with ASD had taken place with siblings. They are discussed next.

#### Future plans from the sibling's perspective

Seven of eight siblings reported no formal family dialogue about future support plans for an adult brother or sister with ASD had taken place; however, most expressed that they envisioned undertaking some future responsibilities after their parents had died or were no longer able to provide support. For example, Gregory, 24-year-old George's brother stated, 'It's never been discussed but it will be my responsibility and I accept it'. Many parents stated that when they were no longer able to care for their adult child with ASD the support role and responsibilities would be carried on by a sibling.

'I think about it [future planning for her adult autistic son, George]. But with his mental health it is more trying to get through a day than to think ahead. He is always with me. At the minute I don't see a time when he won't be, apart from when I am gone and then Gregory [his brother] will be there'.

Grace, mother of 24-year-old George

Grace reported it was an unspoken assumption that Gregory would undertake responsibility and support for his brother after her. She stated she had never discussed the subject with her autistic son George, but would 'when the time came' ask him his preferences and 'try to facilitate them'. Grace expressed access to information and support to enable a parent to initiate future planning was missing. Moreover, she and other family members described the idea of future support planning as a very emotional process. Parents reported putting off the prospect of planning to a later date while simultaneously appreciating the gravity of not planning. Diana, 29-year-old Derek's mother expressed, 'where can I find the right people to carry on where I leave off?' Siblings identified the sensitive nature of the subject as a rationale for non-discussion among family members.

Although continuation of support for his 41-year-old autistic brother after their parent's death had never been 'openly discussed', Matthew reported, 'probably it [future support for autistic brother, Mark] has always been there, although I certainly have never looked at it. At the moment it is a seed in my mind'. The linked lives principle of the life course theory includes the relationship of siblings. Yet, the support they are able or willing to provide for an adult brother or sister with ASD post-parental provision may not be equivalent in quality or

quantity to what parents currently provide. As such, adults with ASD may require greater formal or informal support from various sources. The majority of siblings had moved out of the parental home and reported they would not be able to live with their brother or sister with autism in the future. As such continued co-residence of adult children with ASD with ageing parents may suggest the need for alternative housing post-parental support. Only one sibling, 23-year-old Irving, stated being unable to assume the responsibility of supporting his twin autistic brother, Ian in the future. Irving himself was on the autism spectrum and did not feel capable. At the time of the interview both siblings continued to reside with their mother and were unemployed. She expressed having made no future plans. She stated, 'I think about it, but it is like how am I going to do it?' Moreover, she expressed that doubtless both of her sons would need some future support when she was not alive or able to provide for them. Additionally, when parents were asked if they had an emergency plan should something happen to them unexpectedly, most parents either stated they did not or that the adult with ASD's sibling was their emergency plan; further highlighting the implied future support role they envisioned a sibling would undertake.

## **Chapter summary**

In summary, key findings highlight welfare support needs for adults with ASD in the areas of money management, exploitation risks and independent living. Money management and budgeting difficulties included, but were not limited to: overspending, lending and giving away money, limited understanding of credit and debit, obsessive saving of money, difficulty understanding and organising payment of bills, as well as limited knowledge of the value of different denominations of currency. At the time of the interview, most adults with ASD were receiving family support with managing and budgeting their money. Moreover, future financial security and adequate support with money management and the risk of exploitation were concerns expressed by family members. Contested family perspectives of abilities and support needs for adults with ASD identified through text analysis may reflect executive functioning deficits of adults with ASD and influences of lifelong parental support. Findings suggest adults with ASD may mis- or under-represent their own needs. Moreover, heightened concerns for the safety and wellbeing of adults with ASD post-parental support may account for higher needs reported by family members. Discrepancies could have implications for how support needs are assessed and provided in the future.



Although all parents recognised the value of creating a future support plan for adult children with ASD, only 2 of 16 had initiated any concrete preparations. Given that Price et al (2014) identified the difficulty to, and avoidance of, personal future care planning among older people in general, it is not surprising that few parents had developed future social support plans for adult children with ASD. Similarly, parents of adults with ASD expressed avoidance and overwhelm at the prospect of creating future support plans for their adult children. Expressed reliance on siblings to assume future support, although largely undiscussed, enabled some parents to avoid planning. Additionally, described overwhelm at where or how to begin, separated planning from action for many parents. Uncertainties, contested perspectives of the capacity of adults with ASD and potential support roles of siblings or formal services may delay family preparations for future support plans for adults with ASD. Yet, developing a personal future plan with the adult with ASD building on their capabilities and preferences and designing a network of people and services to meet their support needs is critical. Assuming that families have future care plans post-parental support for adults with ASD may have dire consequences for individuals, families, communities and society at large.

## Chapter 10: Discussion and conclusion

The aim of this research was to investigate the support needs of adults with ASD from the perspectives of multiple family members including adults with ASD, their parents, siblings and partners. It also explored family relationships and role changes over time, and preferences, concerns and expectations for the future support of adults with ASD. The key findings of this study concern the needs of adults with ASD in relation to (i) age differences, (ii) limitations in service provision, and (iii) social networks, (iv) unique adulthood needs, (v) discrepancies in family member perspectives and, (vi) family future plans. Evidence highlights areas of difference and similarity of need between two age groups of adults with ASD and how they are, or are not, currently being met. Additionally findings report how the needs of adults with ASD are anticipated to be met in the future when family circumstances change.

The safety net currently provided through family support and resources for adults with ASD may diminish overtime, with a greater need for formal service support in the future. However, findings demonstrated that there are service limitations to meet the needs of adults with ASD. The findings underscore the concerns of inadequate money management skills, the complexity of meeting them, and the associated risks of vulnerability for adults with ASD currently and for the future. Moreover, identified contested family perspectives in the abilities and needs of adults with ASD emphasise the challenges of assessing and meeting their support needs. This research topic reflects the growing concerns of family members for the current and future support and wellbeing of adults with ASD and the paucity of research in this area.

In critically reviewing the literature for this study, I found adults with ASD are an under-researched population with gaps in knowledge concerning their current and future support needs. Much research on adults with ASD centres on outcomes (educational, vocational, intellectual and social) (Levy and Perry, 2011, Howlin, 2000, Howlin et al., 2004, Fombonne, 2012) and not on support needs. A few descriptive US-based research studies have identified a lack of services and formal support for adults with ASD focusing on transition to adulthood planning, educational, vocational, day and residential services and social participation support (Gerhardt and Lainer, 2011, Shattuck et al., 2012) but there is a paucity of empirical (Turcotte et al., 2016, Cadman et al., 2012), and limited UK-based research on the support needs and service provision for adults with ASD (D'Astous et al.,

2016, Griffith et al., 2012, Cadman et al., 2012).

The quantitative and qualitative mixed method design of this study generated a rich data set informing the research questions: What are the support needs of adults with ASD? How are these needs currently being met? What are the future plans to meet the needs of these individuals? The importance and implications of answering these questions not only impact the lives of individuals with autism, their families, and society at large, but can also inform service provision and policy implementation. The ramifications of being unprepared to meet the current and future support needs of adults with ASD include harmful mental, physical, and economic consequences for adults with ASD, their families, and society. This study distinctively reports the support needs of adults with ASD from their perspective and those of other family members. It provides age group comparison (18-29 and 30+ years of age) between adults with ASD and investigated a broad range of social, physical and mental health care support needs included in the CANDID. In addition retrospective, current and prospective perspectives of the needs of adults with ASD from multiple family members provided a holistic life course position.

This chapter situates the main findings of this study in response to the research questions and in the context of the wider literature. Next, the chapter critically appraises the mixed methods research design and judiciously evaluates the theoretical perspective used. The life course theory principles of the interplay between human lives and historical time, and linked lives relevant to the lived experiences of adults with ASD and their families are analytically evaluated. The chapter offers implications and applications of the findings in regards to individuals, service providers, and policy. Subsequently identified are the strengths and limitations of the study. A number of areas for future research are proposed to build on these findings and continue to provide insight into under-researched areas. The conclusions drawn from this research complete the chapter.

### **Key findings and contributions to the field of autism in adulthood**

In addition to affirmation of the current knowledge base, this research provides a unique contribution to the field of ASD in adulthood. The findings are assimilated and discussed under three headings: (i) significant age differences in experiences and support needs across

the life course, (ii) the current socio-cultural environment for adults with ASD; and (iii) the need for a framework of support to ensure their safety and wellbeing into old age. The implications of the findings inform requirements at individual, family, services, and policy levels and are described throughout this chapter. Unique to this study was the use of a comparative age group analysis, which demonstrates that older adults with ASD (30+ years of age) have greater needs across more areas of general health, relationships and welfare including unemployment, inappropriate behaviour, exploitation, and mental comorbidities in comparison to their younger counterparts (18-29 years of age). To my knowledge no previous research has reported age-related need and support differences in adults with ASD. Moreover, older adults with ASD in this study reported receiving significantly more informal support than their younger counterparts. Such arrangements are not sustainable indefinitely, and suggest that provisions for future support need to be in place to prevent a crisis when circumstances change and current informal support is no longer available. Family future support plans for adults with ASD are reported below after the findings on age differences and the current socio-cultural context for adults with ASD are discussed.

#### **Age differences in adulthood**

Significant age differences in experiences, need, and support provision between younger (18-29 years of age) and older (30+ years of age) adults with ASD across the established categories of health, relationships and welfare were identified in this study. Specifically, almost all older participants stated they currently suffered with psychological distress, anxiety or depression, compared with just over a third of younger participants reporting a need in this area. Moreover, this study's finding demonstrated that the mental health problems of adults with ASD may inhibit their abilities above and beyond their individual limitations associated with ASD. A need in the domain of social relationships was a top priority for all participants; however, it was significantly greater in the older age group compared to the younger age group. Inappropriate behaviour was reported to be a problem for three quarters of the older participants in this study; a significantly greater need than reported by approximately one quarter younger participants. In the domain of welfare benefits, older aged adults also reported a significantly greater need. The heightened need for welfare benefits reported by older adults with ASD is of concern for their current and future wellbeing and requires further investigation. Are they not receiving the benefits they are entitled to or do they not meet

benefit criteria? Is it a matter of limited information or ability completing applications for welfare benefits? Or are welfare benefits not adequately meeting their needs? Answers to these questions are relevant for service providers and policy makers and essential to the safety and wellbeing of ageing autistic adults. In addition, under the domain of welfare, older adults with ASD reported to be at a heightened risk in the domains of exploitation and safety of self when compared with the reported needs of younger adults with ASD in these areas.

Differences in need by age group may underscore disparities associated with life course support provision, situational context, or ageing. This supports the hypothesis that significant historical and social changes in the context of autism may have influenced the current support needs of adults with ASD. Early diagnosis and educational interventions for ASD have been shown to positively affect social abilities and outcomes in later life (Robins et al., 2001). All younger participants received a diagnosis of ASD before the age of 16, whereas the average age of diagnosis in the older group was 35 years of age. The late age at which older participants were diagnosed and limited educational support received may be associated with their higher need in the domains of social relationships and behavioural difficulties. Additionally, for older adults with ASD, being undiagnosed or misdiagnosed, coupled with limited support in early life stages may contribute to high levels of need in mental health reported in this age group. Having fewer social supports, cognitive deficits, the inability to manage one's own finances and difficulties with activities of daily living, has been shown to place elderly individuals at a greater risk of abuse and exploitation (Choi and Mayer, 2000). As autistic adults age they may experience some or all of these risk factors, with support across the life course necessary to ensure their security.

These results confirm findings of previous studies in some areas, yet provide deeper and alternative perspectives on the support needs of adults with ASD. Limitations in support described in Chapters 6 and 7, corroborate findings of previous US based studies reporting limited support services for adults with ASD (Gerhardt and Lainer, 2011, Shattuck et al., 2012, Turcotte et al., 2016). In addition, findings in this study underscore specific areas of unmet support for adults with ASD, for example in welfare benefits. Moreover, this study provides insight into less reported areas of support need for adults with ASD such as money budgeting, exploitation risk and inappropriate behaviour; areas of need that may greatly

impact the wellbeing and safety of adults with ASD if needs are unmet. Specific sample characteristics including high rates of unemployment and comorbidities of mental illness are also comparable with earlier research (Howlin et al., 2005, Ghaziuddin and Zafar, 2008, Fombonne, 2012, Hurlbutt and Chalmers, 2004, Barnhill, 2007). Although previous research has identified that family continue to provide high levels of support to adults with ASD (Povey et al., 2011, Levy and Perry, 2011, Beadle-Brown et al., 2006), older adults with ASD in this study reported receiving almost twice as much informal support, primarily from a sole parent, than did younger adults with ASD. Such arrangements are not sustainable indefinitely, and suggest that provisions for future support need to be in place to prevent a crisis when circumstances change and current informal support is no longer available. Findings relevant to the current socio-cultural environment for adults with ASD are reported next.

#### **Socio-cultural environment of autism in adulthood**

By highlighting the support needs of adults with ASD, the significance of current family support provisions and limited formal services for adults with ASD, the findings of this study contribute to the broader discussion on the sociocultural environment of autism in adulthood. This thesis shows how adults with ASD and their families are embedded in historical, social and political context. The contrasting socio-historical experiences of parents and adults with ASD in receiving a diagnosis and support described in Chapter 7, identified social and cultural changes over time in the awareness and resources for ASD in childhood and underscored the current void of both in adulthood. While adults with ASD and their family members acknowledged their relief and the knowledge associated with a diagnosis of autism, this thesis has demonstrated how adults with ASD remain segregated rather than integrated into society, with family continuing to meet their social, functional, financial and emotional needs. Findings highlighted the liminal status of adults with ASD, describing them as living betwixt and between the social structure of society, socially unrecognised and needing but not receiving support services. While the Autism Strategy in the UK acknowledges the necessity of assessing needs among adults with ASD it does not address how services will meet these needs (Walsh and Hall, 2012). Few participants reported having a needs assessment and most reported an array of unmet service support. Parents expressed a lag effect between written policy directives and the practical application of support services for adults with ASD.

Findings on the social welfare support needs of adults with ASD highlight that there is no 'cultural script' for adults with ASD. Cultural scripts form an important part of everyday understanding and interactions with different people. However, there is no tradition of what adults with ASD are like or what they do, which creates difficulties for understanding, planning and providing for them. Moreover, findings suggest the normative lens of the cultural script of adulthood (independence and social roles) cannot be applied to adults with ASD. Cultural scripts clearly articulate the norms, values and practices for both cultural insiders and outsiders (Goddard and Wierzbicka, 2004). Cultural scripts provide a shared interpretive background against which individuals position their actions and interpret those of others (ibid). Adults with ASD represent a new complex and variable social and cultural identity which demands new understanding, interactions and accommodations. Different organisational practices, societal processing, and support are necessary to meet their current and future support needs.

Normative age-chronological timing of life transitions are widely accepted as socially constructed rules that specify how individuals are expected to think or behave (Heckhausen and Krueger, 1993). Independent living is part of the normative cultural script of adulthood (Pillemer and Sutor, 2002). Yet for many adults with ASD independent living was not an inevitable process, and for most attainment may be associated with the need for a wide range of support. For the majority their future remained imagined, based perhaps on normative adult expectations that they see others without autism doing and on what they think they are expected to say in an interview. Largely, it was not based on what they were currently doing, nor based on the actions of other adults with ASD that they know. This is not to say that their imagined futures are not realistic or attainable but rather to emphasise the disconnect between the present and the future and underscore the skills and support necessary to bridge the divide. Moreover, parents also want a future for their child that is partly based on this cultural script, albeit a supported future, and society's wider expectations of adults. However, parents also realise that there are difficulties in achieving this because of difficult past and present experiences and some appreciate they may be building an imagined future that they will likely not see. Siblings of adults with ASD seem to be drawing on concrete accounts or witnessed events of past and present difficulties and perceive that to be the continued future. Although

currently they are more removed from the situation, they see the situation perhaps more dispassionately and more objectively than the adults with ASD and their parents. However, they too may be relying on an expected script for an imagined future of assuming responsibility for a brother or sister with autism, with actual practicality less likely to be feasible.

An increasing number of studies are exploring ageing and autism (Happé and Charlton, 2012, Perkins and Berkman, 2012), but few report the personal experiences and subjective support needs of adults with ASD. In accordance with extant research few adults with ASD in this study were employed (Barnhill, 2007, Howlin et al., 2004, Eaves and Ho, 2008), living independently (Billstedt et al., 2005, Howlin, 2000, Howlin et al., 2004), had married or were in long-term relationships (Howlin et al., 2004, Eaves and Ho, 2008). The high rate of comorbidities of mental illness found in this study were in line with previous studies (Fombonne, 2012, Ghaziuddin and Zafar, 2008). Additionally, the descriptions of mental illness among adults with ASD from their perspective, and those of their family members, contributed to an understanding of the compounding effects of comorbidities of mental illness on their daily lives. Mental illness for some adults with ASD was debilitating and further imposed restrictions in social interactions and engagement in employment. Although mental illness was explained as a pathway to support services for adults with ASD, many participants described an unmet need in this area. Moreover, the effects of mental illness on the adult with ASD filtered out to impact the lives of family members. Mental illness featured prominently as a family concern for the future wellbeing of adults with ASD, particularly when current family support may be absent or change. Parents and partners expressed worry about the impact of their loss, and the loss of their support in the future, on the mental wellbeing of adults with ASD.

Furthermore, the contested family perspectives of ability and support need of adults with ASD explained in Chapter 8 has implications for how the support needs of adults with ASD are assessed, recognised and provided. Although adults with ASD reported high levels of support needs across a wide range of areas on quantitative measures in this study, they generally detailed having fewer needs in qualitative interviews. However, their parents, siblings and partners described them as having less life skills and requiring greater support



needs than they did themselves. These contested perspectives in ability and need have implications for how and with whom the assessment of needs of adults with ASD is conducted. Chapter 3 of this thesis reiterates that the allocation of services in the UK is structured on the medical model of disability with access established by levels of need; however, the difficulty some adults with ASD have expressing their needs and completing forms reported in this study, may falsely contribute to decisions of their ineligibility of support services. Furthermore what support needs are assessed may be essential to the wellbeing of adults with ASD. High levels of social support needs, in the areas of social activities and relationships, life skills, employment and exploitation risk, were largely unmet by formal services, limiting potential societal contributions and possibly the quality of life of adults with ASD.

High support needs in the domains of money management, exploitation, and safety of self, previously less often reported areas of need among adults with ASD, underscored potential endangerments in the current socio-cultural environment for adults with ASD. Limitations and difficulties in the ability to manage and budget money were reported equally among all adults with ASD in this study, while the risk of exploitation and safety of self were stated to be significantly greater for older than younger aged adults with ASD. Although parents and family members had established efforts to minimise harm for adults with ASD, this study revealed they cannot eliminate risk. This was particularly evident in regards to internet and online communications and transactions. Although adults with ASD may have computer literacy to access online sites for communication, dating, and making purchases, their limitations in money management, social and communications skills and decision making placed them at risk of emotional, physical or financial harm. As discussed in Chapter 9 technological progress, choice and consumerism have socio-cultural implications for how information, social interactions, goods and services are accessed and acquired with potentially challenging consequences for adults with ASD. Extant research on the risks and safety of the internet focuses primarily on children (Livingstone et al., 2010), dating (Couch et al., 2012), identity theft and fraud (Milne et al., 2004). Research in relation to technology and autism tends to focus on the positive contributions of assisted and interactive technology primarily for children with autism (Bölte et al., 2010). No research was found that explored the possible negative implications of technology for adults with ASD, such as the risk of abuse, both social

and financial emphasised in this study. Furthermore, few resources are directed to critical social support needs such as money management and social vulnerabilities, including isolation and abuse of adults with ASD, central concerns of parents and family members for the future when they will not be alive or able to maintain current support.

#### **Need for a framework of support**

The implications of the findings underscore the necessity for a framework of preparation and provision to meet the current and future support needs of adults with ASD. This study has demonstrated that adults with ASD require a wide range and coordination of services and support to function in the community. It has highlighted that there is a gap between level of need and what is currently available. Furthermore, the framework for support services is based on a disability model and not a cultural script of the complex support needs of adults with ASD. The difficulty adults with ASD may have in expressing their needs, has implications for how support needs are assessed and may be associated with their invisibility and under-support by formal services. Moreover, support needs unique to adulthood such as in the area of money management require unique ways of meeting them to respect the dignity of adults with ASD. Unmet needs of money management may have considerable implications for the safety of adults with ASD and their ability to achieve independent living.

A framework to meet the diverse support needs of adults with ASD must articulate and integrate the major concerns of several stakeholders including adults with ASD, their parents, siblings and partners as well as professionals and service providers. Without a cultural script for adults with ASD, designing and synthesising a framework to meet the diversity of their support needs for transitioning, bridging and planning a future beyond parental support may be inconceivable. Moreover, the findings of limited social support networks of adults with ASD inferred the potential of diminished family support in the future. The social network of adults with ASD starts and ends primarily with the relationships, support and resources provided through families. Few adults with ASD were found to have bridging or linking social networks which diminished their access to wider support systems and resources as a safety net should they lose family support.

Although most siblings of adults with ASD expressed anticipating some responsibilities of support for a brother or sister with ASD in the future, it may be less feasible or practical than they imagine and certainly not to the same high level that parents are currently providing with a greater need for formal services in the future. In addition, parents and family members of adults with ASD expressed the complexity of the liminal space of planning or not planning for the future, knowing plans need to be made but not being ready or able to act on making them. Few families had developed future support plans for their relatives with ASD. The current limited formal services for adults with ASD identified in this research suggests service providers may be ill prepared to meet the future support needs of adults with ASD when current levels of informal support may be absent. Additionally, the findings in Chapter 8 intimate that parents of adults with ASD cannot complacently rely on their other children to assume the full responsibility and support for their brothers or sisters in the future.

This research indicates there is a critical need for the development of an informal and formal framework of preparation and support provisions to meet the needs of adults with ASD to ensure their safety, dignity and wellbeing as they age. Without such planning and support, there is an increased risk of social exclusion, harm and health problems, particularly mental illness. In the UK, much progress has been made, and continues to be, through government legislations, the development of local partnerships boards, awareness, training, increased services (particularly diagnostic), and ongoing research. However, there is still a lot of work to be done in sectors such as social inclusion and equal opportunities with effective support, and services to benefit adults with ASD and enhance their ability to contribute to their communities and society.

### **Mixed methods and what they added**

To date, little research in ASD in adulthood has utilised a mixed-methods approach. Typically research with adults with ASD has used either quantitative or qualitative research methods. The mixed-method approach afforded a wealth of data to demonstrate statistically significant differences, and qualitative patterns and themes. Using quantitative and qualitative approaches can provide different perspectives of the same phenomena and as such offers more and richer evidence (Creswell et al., 2011). This study sought to not only identify and quantify the support needs of adults with ASD but also to explore the qualities of these needs

through face to face semi-structured interviews with family members. The two databases can converge in understanding of the research questions (Tashakkori and Teddlie, 2010). The use of questionnaires in Stage One provided background information and an evidence base for deeper exploration involving in-depth, semi-structured interviews at Stage Two. Moreover, findings from the quantitative and qualitative studies formed a complementary and exploratory basis to support confidence in the results. The triangulation between methods helped minimise the bias that may result from using a single method of data collection and provided a deeper, wider perspective of the support needs of adults with ASD. Triangulation of reported findings between the support needs reported in Stage One and those that adults with ASD and their family members described in Stage Two provided contested perspectives of the needs of adults with ASD. Furthermore, the use of both methods provided greater understanding of the support needs of adults with ASD than either quantitative or qualitative methods alone may provide (Creswell et al., 2011). This was evident in differences in need reported by adults with ASD on quantitative questionnaires and in qualitative interviews with implications for how needs assessments are conducted. Additionally, the perspectives of multiple family members provided a more comprehensive identification of the needs of adults with ASD.

The design of a two stage, mixed method also afforded the opportunity for the researcher to meet on two separate occasions with the adults with ASD. A certain level of rapport between the researcher and the adult with ASD was developed through the mixed method research design. For most adults with ASD interviewed at Stage Two, the initial meeting to complete the quantitative questionnaires at Stage One provided an introduction to the researcher and built rapport to enable a more familiar relationship for the following qualitative interviews that took place at a later date. However, as a cross-sectional study, the quantitative questionnaires and the semi-structured interviews took place at one point in time and can therefore only represent the participant's current situation and perceptions. The use of a longitudinal methodology collecting questionnaire data and interviewing adults with ASD and their family members across the life course, from childhood through to old age would demonstrate more clearly changes in roles, relationships, needs, perceptions and wishes and would provide greater depth and clarity but is beyond the scope of this thesis. Retrospective information about past experiences and family relationships across the life course is subject to

recall bias and may not be an accurate account of occurrences. However, triangulations of reported perspectives of multiple family informants were used to try to verify individual viewpoints and experiences against others. Additionally, the similarities of within age group comparatives further supported the likelihood of the described experiences in relations to the socio-historical time.

There are also limitations associated with the measures and how they were used in this study. The CANDID is a standardised needs-assessment instrument for adults with learning and developmental disabilities and mental health problems, and the Client Service Receipt Inventory (CSRI) gathers retrospective information on service utilisation. While the CSRI was adapted for adults with ASD, the CANDID is not particular to autism and may be missing key domains of support and service use specific to adults with ASD. Questionnaires were administered in a face-to-face meeting, with the researcher reading and recording responses for each question in an effort to provide clarity and regulate presentation. Greater validity may have been achieved had a second informant such as a parent, sibling or partner of an adult with ASD also completed these questionnaires and the data compared. A number of initial questionnaires responses were reviewed with the research supervisor to ensure the data conceptualised in the study was being accurately collected before proceeding with their use. Data collection via face to face interviews offered the opportunity for clarity and allowed the researcher and participant to engage in the concept under scrutiny and probe areas of interest. However, it is possible data collection via less intrusive means such as telephone or online may have offered wider participation to a wider audience. Some adults with ASD had more difficulty answering questions and expressing themselves. At times closed ended questions were asked for simplicity when open ended questions seemed challenging to an individual, which may have introduced bias through leading questions. However, the strengths of the research methods design enabled quantitative and qualitative comparison and analysis between individuals and age groups to answer the research questions and to provide a comprehensive view of the support needs of adults with ASD.

### **Critique of life course theory**

The life course perspective provided a useful conceptual lens to explore the experiences and relationships of families of adults with ASD within the context of historical and social

circumstances. The findings reveal that the experiences of adults with ASD and their family members are embedded in historically and politically situated practices and the construction of autism. The lived experiences of older adults with ASD and their family members, as a result of an unknown diagnosis, can be partially explained by the historical social context in which they lived in line with the life course theory. Consistent with previous research introduced in Chapter 1, the interplay between human lives and historical time was evident in the experiences of diagnosis and availability of support in the two age groups of adults with ASD in childhood. The majority of older adults (30+ years of age) did not receive a diagnosis of autism in childhood and their parents described limited support available to them growing up in the 1960s, 1970s and 1980s. Although parents reportedly sought a diagnosis for the differences they observed in their children, perhaps due to the limited awareness of autism at the time (Wing, 1985) or the restrictive diagnostic criteria (Eisenberg and Kanner, 1956, Knobloch and Pasamanick, 1975) most remained undiagnosed or misdiagnosed until many years later in adulthood. Whereas younger adults with ASD (18-29 years of age) grew up in a historical time, with greater awareness of autism and expanded diagnostic criteria and as such they primarily received a diagnosis in childhood. Moreover, some younger adults with ASD and their parents described receiving an array of educational and informational support up until adulthood. Findings from this research have shown how the impact of changes in the medical understanding, social awareness and resource provisions for autism that have occurred over time, have influenced patterns of interactions and relationships within the families and communities of adults with ASD.

The linked lives of parents, siblings, partners and adults with ASD are emphasised in this study through close family bonding networks. This thesis demonstrated that parenting a child with ASD who does not meet normative developmental stages or transitions through the spheres of education, work, family, and retirement is both challenging and bonding. Although parents described relationship changes as their child with ASD reach adulthood, many parenting responsibilities and roles did not change as normative milestones of adulthood were not achieved by their children. The role of providing support for an adult child with ASD extended over the lifetime for many parents. Moreover, the impact of ASD is a shared family experience as demonstrated through sibling and partner relationships in this study (Woodgate et al., 2008). Although siblings are located within the family life course, the quality of their

relationship and duration of their linked lives may change over time. Previous research has identified the stress, growth opportunities, and outcomes in adulthood for siblings with a brother or sister with ASD (Orsmond et al., 2009, Orsmond and Seltzer, 2007a). The sibling relationship with their brother or sister with ASD may become increasingly more important as their parents age. However, the social pattern and complex connections of families with an adult with ASD does not fit neatly into the life course perspective where linked lives are age-differentiated, by generational positions, which define roles and relationships over time. Specifically, the anticipated intra-generational role of assuming responsibility and support for an adult brother or sister with ASD by a sibling post-parental care extends beyond the normative relationship of the linked lives principle.

Although the life course theory includes continuity and change, a life course of liminality, living on the boundaries of societal awareness, medical recognition and social support has not previously been described in life course research. Moreover, while liminality is typically understood as a temporary space in between, this research has underscored the continual betwixt and between social, emotional and functional liminal existence experienced by many adults with ASD across the life course. Liminality characterises the ambiguity and disorientation parents and older adults with ASD described experiencing without a diagnosis of autism in childhood, compounded by the lack of societal awareness and support. Parents expressed feeling socially isolated with unanswered questions and blame; adults with ASD described not 'fitting in' and years of being bullied. Without a reason for their differences or support with challenges they lived in a state akin to liminality. However, although a diagnosis of autism in adulthood provided some answers and relief; adults with ASD remain liminal, not fully assimilated in society. For example, few adults with ASD had assumed normative adult roles and responsibilities attained through employment, social relationships and independent living. Moreover, the findings of limited communication, life and money management skills, and high comorbidities of mental illness reported by, and of, adults with ASD rendered them ill prepared to transition to independent living and to assume roles and responsibilities of adulthood without adequate preparation and support. Adults with ASD and family members reported formal support services were missing or inaccessible.

Adults with ASD present a complex intersection between abilities and impairments with many of their support needs being just outside the border of policy guidelines and the structure of needs based service support eligibility. Socio-culturally adults with ASD remain unrecognised and not integrated or supported into defined roles and responsibilities associated with adulthood. Without vocational, social and life skills support adults with ASD may not be able to achieve independent living or other socio-cultural definitions of adulthood. As such many adults with ASD remain living in a liminal space being neither children nor adults, but still living with, and dependent on, the support of their parents and other family members. The life course perspective does not adequately apply to the liminal life course experiences and needs of adults with ASD.

Moreover, are the societal norms and expectations of adulthood, including objective and subjective ideals of friendship, education, employment and independence the desired goals of adults with ASD? Or are more diverse preferences and outcomes their goals? Supporting this assertion Billstedt and colleagues (2011) using a newly constructed 'autism friendly/environment/quality of life rating scale re-evaluated adulthood outcomes of participants from a previous follow-up study. They reported different outcome findings were dependent on what was measured. The impact of the person-environment fit is not included in the life course perspective yet may greatly influence the wellbeing and quality of life of adults with ASD. A perspective focusing less on normative age related criteria and more on the individual's concepts of adulthood and their subjective quality of life may be better suited to understand the life course of adults with ASD.

This thesis suggests that with little recognition of, or support for the needs of adults with ASD they live suspended between a state of isolation and inclusion. Currently without a defining cultural script of autism in adulthood to guide awareness and inclusion into communities and society, adults with ASD remain in a liminal cultural space. Moreover, a focus on lives lived between the spaces of the socio-cultural context may capture a wide range of individuals whose life course experiences do not fit neatly within the current scope of the life course perspective.



## **Strengths and limitations of the study**

This study is the first to my knowledge to quantitatively investigate and compare the support needs in two age groups of adults with ASD using standardised self-report measures. However, the small sample size ( $n=74$ ) limits generalisation of the findings. Although the sample size ( $n=74$ ) is considered small by quantitative standards, each decade from late teen to sixties was represented in the sample to provide a broad indication of support needs of adults with ASD across the life course. The intention of the qualitative paradigm to understand the social world from the perspective of adults with ASD and their family members through detailed descriptions of their experiences and insights was achieved. No previous research has qualitatively explored the current and future support needs and preferences of adults with ASD from multiple family perspectives. This research therefore makes important contributions to the understanding of age differences in support needs among adults with ASD, and to the broader discussion on the sociocultural environment of autism in adulthood. It underscores the limited planning for the future by families and society to meet the needs of adults with ASD post parental support.

Exploring the needs and support of adults with ASD is within the parameters of key research priorities expressed by the autism community in the UK, which include: to make a difference in people's day-to-day lives and for greater involvement of the autism community in research (Pellicano et al. 2014). The portrayal of the experiences, needs, and preferences of adults with autism is important to understanding what these needs are and how they can be met through support. Moreover, understanding the needs of adults with ASD from their perspective and that of their family members can help inform services and policy makers to ensure that resources reach where they are most required. As such, findings could have translational benefits to enhance the lives of adults with ASD and their families.

However, in drawing conclusions about the meaning of the findings presented here, certain limitations must be addressed. Firstly, the small sample size may have contributed to the differences reported between age groups. Particularly, the limited sample of older adults with ASD may have biased the findings, with significant relationships and support needs missed. An epidemiological sample and a larger sample size, particularly one with a more equal distribution of younger and older aged adults with ASD may be more representative of the

support needs and family relationships in adults with ASD. Secondly, all participants were known to services and recruited through various clinics and therefore, it is possible that this was not a random sample of adults with ASD but rather a group that shares certain common characteristics and may not be representative of the population of adults with ASD. The source of the sample, drawn from the Behavioural Genetics Clinic and the Department of Forensic and Neurodevelopmental Sciences database may have biased the level of mental health comorbidities in this sample. It is possible findings may be different if the sample included adults with ASD from different sources other than exclusively recruited from health care services. However, the prevalence of comorbid mental illness in adults with ASD in this study was within the range reported in previous research. Thirdly, although no measures of severity of autistic features and level of cognitive functioning were used in this study, the adults with ASD in the sample were relatively 'high functioning', which is also not representative of all adults with ASD. As such the generalisability and transferability of the support needs of these participants to the population of adults with ASD is limited. However, given parallels with previous research, triangulation with different family perspectives, internal validity associated with the research design and careful data collection, it is probable that the issues highlighted in this study are a good reflection of the support needs adults with ASD and the limited preparations and availability of services to meet their future needs.

The quantitative findings are all self-reported perspectives of participating adults with ASD and not documented verification of needs, support receipt and service use. Self-reported data is limited by the fact that it rarely can be independently verified. Participants may not remember or accurately remember experiences or events that occurred in the past and they may minimise or embellish events as more or less significant. However, self-reported information presents the individual's perspective. Additionally, lack of comparative CANDID and CSRI data from parents, siblings, or partners, which may have enhanced contested family perspectives garnered in interviews, is another limitation. All participating adults met mental capacity criteria and ethical considerations of answering questions were explained prior to beginning the questionnaire and interview. Recording and acknowledging their personally expressed needs, support provision and health care service use provides first-hand knowledge of the resources they need and access, as well as validating and respecting their autonomy. Self-report measures were deemed an effective method for answering the

research questions of the current study and do not diminish the quality of the findings. The findings may be important to determine where and how changes in support and service delivery system may be most useful.

Although, the inclusion of patient and public involvement (PPI) informed the design of the NIHR Crossing the Divide study on which this research built, I was not able to include PPI in this PhD project, which could be considered a limitation. The wider study involved users, carers, and their representatives as co-applicants (e.g. National Autistic Society and Autism Speaks). They helped design the study, monitored the progress, and took an active part in carrying out the research. PPI may be particularly important in research exploring the support needs of adults with ASD as it is with them, rather than about, or for them. The involvement of patients, the public, and service users at multiple points throughout the research process has been shown to be beneficial to the design, implementation, and results of the research (Stewart et al. 2011). Moreover, it empowers individuals and communities in the shaping of health and social care services (Mockford et al. 2012). Additionally, reports have revealed that adults with ASD and their family members want to be included in research (Wallace et al. 2013). The inclusion of an adult(s) with ASD in the study to offer advice, comment on and develop the research materials, and undertake interviews with research participants may have highlighted different priorities and support needs of adults with ASD. Including PPI may have identified issues, concerns, and highlighted areas of preference that should be acknowledged and included in the findings and conclusions on the support needs of adults with ASD.

Lastly, a key procedural limitation in this study warrants mention. The final questions on the interview guides ask what would be helpful to make future support plans for a family member with ASD. However, after the first few interviews, I stopped asking this question of subsequent participants. Although this is important information since the majority of participants expressed not having a future support plan, I felt that it was unintentionally condescending, implying that they should have, or should be, developing a future support plan. Although not having this information does not diminish the findings that most families did not have concrete future support plans for adults with ASD, it may have provided a key

theme as to why or what is needed to enable them to develop plans, which merits future research.

### **Suggestions for future research**

Although the differences observed in this study may represent valid differences, the results also may differ because of the small sample and sampling limitations. While the quality of the sample is important, a larger sample is more representative of the population and limits the influence of outliers or extreme observations. Repeating this study on a larger scale could produce results among variables that are significantly different and allow greater comparison. As such a larger sample would broaden the range of possible data and form a better picture of the support needs, concerns and support provision of adults with ASD. Currently, similar research is taking place in the UK (National Autism Project, 2017). However, cross-sectional research only provides a snap shot at one point in time. An understanding of the support needs of adults with ASD and how these needs are or are not being met would benefit from a longitudinal approach that would offer evaluation of changes in need, and effective informal and formal support services over time.

The process of this research highlighted several areas for potential future research that would add to the current knowledge of support needs for adults with ASD and potentially enhance meeting them. These recommendations build specifically on three particular elements of this research including the limited social relationships of adults with ASD, achieving family future support and the assessment of support needs. Further research suggestions call for participatory research to develop opportunities for social relationships and to expand the support networks of adults with ASD, a longitudinal study exploring family support trajectories, and a quantitative or mixed method design with a comprehensive assessment tool to evaluate the preparedness of adults with ASD for independent living. Each recommendation is briefly validated and explained.

The present study found a high yet unmet need for social relationships for adults with ASD. It provided quantitative and qualitative data on their relationship abilities, circumstances, and experiences. Although much research has focused on improving the social skills of children with ASD many adults with ASD are not diagnosed until adulthood (Punshon et al., 2009).

While some adults with ASD may prefer to be by themselves, most adults with ASD in this study expressed wanting to develop more friendships and social relationships than they currently had. However, there is little research examining this aspect of autism spectrum disorders in adulthood or strategies to facilitate successful relationships (Orsmond et al., 2004, Howlin et al., 2000). Through a participatory action research (PAR) design, strategies to improve relationship skills and propositions to advance and increase social opportunities for adults with ASD could be identified and developed. Participatory action research (PAR) is an approach to research in communities that emphasises participation and action (Walter, 2009). It is based on the premise that research and action must be done 'with' people and not 'on' or 'for' people (Bradbury and Reason, 2014). PAR affirms that experience can be a basis of knowing and that experiential learning can lead to a legitimate form of knowledge that influences practice (Baum et al., 2006). Adults with ASD, their family members and community service providers may be included among research participants with the aim to develop practical and accessible social opportunities to meet the needs of adults with ASD. PAR pays careful attention to power relationships, advocating for power to be deliberately shared between the researcher and the researched as partners in the whole research process. This includes selecting the research topic, data collection and analysis, and deciding what action should happen as a result of the research findings (Bradbury and Reason, 2014). The process of PAR should be empowering and lead to people having increased control over their lives (Ozanne and Saatcioglu, 2008). Improving the social skills and opportunities for social engagement for adults with ASD may also extend their social network and access to different resources.

Due to time constraints and resources this study used a cross-sectional research design to explore sibling relationships and their anticipated future support for a brother or sister with ASD. However, without longitudinal research it is not possible to draw conclusions about the family support trajectory. Future studies could be conducted that follow adults with ASD and their siblings through the transition of support post parental care. Previous research exploring sibling support post parental care for brothers or sisters with intellectual disability found the sibling support to be of short duration and not a permanent arrangement (Bigby, 1997). Investigating longitudinally the pre-transition, transition and post-transition process of support for adults with ASD may help inform service providers and raise awareness of

additional resources necessary to facilitate the process. It may help identify the characteristics of siblings who assume future support and detail the roles they provide. Moreover, their support needs to fulfil these roles may be distinguished and delivered. In addition the wellbeing of adults with ASD in these family support arrangements could be explored.

This study has suggested that how and by whom the support needs of adults with ASD are assessed may influence their eligibility for support services. Additionally, it underscored how differently family members perceived adults with ASD's abilities to live independently. More research is needed to explore this issue further. In particular the concern is that essential support needs to ensure the safety of adults with ASD may not be currently being assessed. Given that ideally most adults with ASD and their family members expressed the desired goal of independent living, future research using an assessment tool for independent living skills may highlight specific areas of support or life skills training to prepare adults with ASD for the future post parental support. The Ansell- Casey Life Skills assessment consists of 113 items that assess skills, knowledge, and awareness in seven areas (Daily Living, Self-Care, Relationships and Communication, Housing and Money Management, Relationships and Communication, Career and Education Planning, and Looking Forward) (Nollan et al., 2000). Originally, designed to assess the preparation of youth transitioning out of foster care to independent living it can be useful for other populations including adults with ASD (ibid). It identifies self-sufficiency and life skills that have been mastered and those yet to be learned. Conducting a quantitative or a mixed method study using this measure may provide a more detailed assessment of how prepared an adult with ASD is to live independently and underscore areas and skills that need to be developed to ensure their safety and wellbeing.

## **Reflexivity**

Reflection emphasises the intention to learn, making connections between new and existing knowledge and experiences (Moon, 2001). This reflexive section acknowledges my role and experiences in this research. It includes looking inward and outward in regards to the experiential journey of undertaking a PhD (Johns, 2009). I briefly describe what I was trying to accomplish, how I influenced, and was influenced by, past and current experiences that led to my personal and professional growth. It concludes with how I can take what I have learned

forward, reflecting on the gap between policy and practice, actions required and possible ways of improving the situation for adults with ASD and their families (Rolfe et al., 2001).

The process and evolution of this research included not only the experiences of decision making, personal interactions and learning but also the inward journey incorporating my feelings and thoughts. Equal to the outward acquisition of research skills and professional development, my internal feelings had to be acknowledged and managed throughout the process. Emotions of excitement, fear and frustration were my constant companions. I learned as much about myself as I did how to conduct a study and be an academic researcher. While I did not keep a journal over the course of my study, certain experiences and interactions are imprinted on my mind and drive my passion to make an impact in the lives of adults with ASD and their families. Having had a career in nursing and raised my four children, I returned to academia and completed two master's degrees which propelled my interest and desire to undertake a PhD. The impetus for a thesis exploring the support needs of adults with ASD came from interactions with youth on the autism spectrum and their family members in my master degrees. Parents and grandparents voiced concerns for the future and the support of their children in adulthood when they would not be alive to support and safeguard them.

I do not have a child, a sibling or a family member with ASD. Nonetheless, my past experiences have influenced my knowledge and perspective. I worried how the participants would perceive me and my interest in the support needs of adults with ASD. Undoubtedly, despite my efforts to build rapport with interviewees, my appearance, questions, age and accent may have influenced their responses. As none of the participants in this study were previously known to me, at the point of interview they were effectively speaking to a stranger. Given that many adults with ASD identified high levels of anxiety and stress associated with meeting new people, I was both saddened by the prospect of causing them distress, and grateful that they were able to rise to the challenge to participate in this study. I was a similar age to many of the parents, some adults with ASD and their partners and siblings that I interviewed in this study. Additionally, some of the adults with ASD were of similar age to my children. I could not help but reflect on their circumstances and consider how I would have reacted, felt or acted in their place, had I been the parent, or sibling. I have learnt a great deal from the different lives and experiences, hopes, wishes, struggles and fears shared with

me by participants. Each presented their unique experiences and perspectives, set within a family culture and life events which has made me realise that each individual within a family has to be considered as an entity in their own right, and that life events and circumstances over the life course affect each individual in different ways.

The questionnaires and interviews with adults with ASD and their family members provided the informational building blocks of this study, yet they also underscored how little I understood about the lived experiences of ASD and how profoundly it had shaped their lives. I feel that this study provided a platform for them to voice their joys and fears and validated their frustrations. I listened to their accounts and acknowledged their challenges and strengths but I had little reference in my past experiences to draw on. I was humbled by their genuine and unassuming demeanour. Conflicting perspectives between family members provided a glimpse of the fragility of the present semblance of order and the possibility of impending disorder. That things could fall apart in a moment was a constant worry. I empathised with parents who tread a fine line maintaining the dignity and security of their adult children with ASD and understood the longing of the adults with ASD to be autonomous. Partners and siblings shared great insight, patience and frustration. I recall often feeling exhausted following interviews but with a renewed fervour in effort to make a difference in their lives. As such, I will take what I have learned from this experience, to my further research and efforts to endeavour to create tangible change. For example, closing the gap between policy initiatives and actual availability of services; inclusive, participatory efforts to improve social opportunities for adults with ASD; and support for their siblings as they assume responsibilities post-parental care for brothers or sisters with ASD. I have gained a new perspective and understanding of the lives of adults with ASD and their family members through this experience. Moreover, my academic skills including research, writing and presenting have also developed and improved through this PhD journey.

## **Conclusions**

To my knowledge, this study is the first to explore the support needs of adults with ASD from a holistic family perspective, including adults with ASD, their parents, siblings and partners



using a mixed method, comparative age group research design. The findings of this research add to the knowledge of the support needs and family relationships of adults with ASD with implications for families, practice, service delivery and policy. Adults with ASD have high levels of need and unmet needs across a wide range of areas, particularly older adults with ASD. Understanding the experiences and needs of older adults with ASD has the potential to affect the support offered and available to younger adults with ASD. Parents are the supportive backbone and critical to the quality of life of their adult children with ASD. Family members universally expressed concerns for future vulnerability and safeguarding of adults with ASD. This study emphasises a vital need to build a broader social network and create future support plans to ensure the dignity, safety and wellbeing of adults with ASD across their life course. Hopefully, the dialogue with adults with ASD, their parents, partners and siblings encouraged them to recognise future plans as living documents which need to be modified as appropriate over time but are of significant importance to be created now. Moreover, this vital conversation about future support plans needs to be addressed by advocates, service providers and policy makers.

The findings of this research emphasised the wide diversity of practical, social and psychological support needs of adults with ASD and the limited support service available to meet them. Commissioning and services need to be available at the local level. Findings can serve as a source of credible data to understand the needs and unmet needs of adults with ASD so that resources can be allocated and services implemented. Contested perspectives of the needs of adults with ASD offer insight into how and with who needs assessments for adults with ASD are conducted. Moreover, the limited current services suggest that providers may be unprepared for the future when adults with ASD transition out of parental support. Finally, there appears to be a disconnect between policy initiatives and implementation of services for adults with ASD. Moreover a gap exists in policy to plan to provide support and services for adults with ASD in the future when family no longer maintains this role and/or to assist siblings to transition to assuming various responsibilities.

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## Appendix A: Ethics committee approval letter



### Health Research Authority

#### NRES Committee London - Camberwell St Giles

Bristol Research Ethics Centre  
Level 3, Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT

Tel: 01173421334  
Fax: 01173420445

09 July 2013

Professor Philip Asherson  
Professor of Molecular Psychiatry & Honorary Consultant Psychiatry  
MRC SGDP Centre, Institute of Psychiatry, South London and Maudsley NHS  
SGDP Building  
Institute of Psychiatry  
De Crespigny Park, London  
SE5 8AF

Dear Professor Asherson

**Study title:** Service use and needs among those with an ASD during the transitional years from adolescence to young adulthood  
**REC reference:** 09/H0807/71  
**Amendment number:** 6  
**Amendment date:** 21 May 2013  
**IRAS project ID:** 31796

Thank you for submitting the above amendment, which was received on 01 July 2013. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

#### Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	6	21 May 2013
Protocol	6	21 May 2013
Stage 1: Clinic Invitation letter Adult ASD	5	21 May 2013
Stage 1: Clinic Invitation letter Parent	5	25 May 2013
Stage 1: Adult ASD Invitation letter	5	21 May 2013
Stage 1: Parent Invitation letter	5	21 May 2013
Participant Information Sheet: Stage 1: Parent	5	21 May 2013
Participant Information Sheet: Easy read	5	21 May 2013

Participant Information Sheet: Stage 1: Adult with ASD	5	21 May 2013
Stage 1: Study form Parent	5	21 May 2013
Stage 1 Study form Adult with ASD	5	21 May 2013
Stage 2: Sibling Invitation letter	1	21 May 2013
Stage 2: Parent Invitation letter	1	21 May 2013
Stage 2: Adult with ASD Invitation letter	1	21 May 2013
Participant Consent Form: Service needs	5	21 May 2013
Participant Information Sheet: Stage 2: Easy read	1	21 May 2013
Participant Information Sheet: Stage 2: Sibling	1	21 May 2013
Participant Information Sheet: Stage 2: Parent	1	21 May 2013
Participant Information Sheet: Stage 2: Adult with ASD	1	21 May 2013
Stage 2: Study form	1	21 May 2013
Participant Consent Form: Stage 2	1	21 May 2013
Stage 2: sibling topic guide	1	21 May 2013
Stage 2: Parent topic guide	1	21 May 2013
Stage 2: Adult with ASD Topic Guide	1	21 May 2013

#### Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

09/H0807/71:	Please quote this number on all correspondence
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Yours sincerely



**Miss Christine Hobson**  
Committee Co-ordinator

E-mail: [nrescommittee.london-camberwellstgiles@nhs.net](mailto:nrescommittee.london-camberwellstgiles@nhs.net)

Copy to: *Ms. Jennifer Liebscher, SLaM/loP R&D Office*  
*Dr Karen Glaser*

## Appendix B: Recruitment documents

### Stage One: Adults with ASD invitation letter



University of London

Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of Child  
and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous, Ms. Hannah Hayward*

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*Tel: 02078485359; Tel. 07895267597*

### **Adult with ASD Invitation Letter** **21.05.2013 version 5.0**

Date

Address

Dear Mrs./Mr.

You and your family took part in an earlier research study lead by Professor Declan Murphy. We would like to thank you for your earlier participation in this project.

Funding has now been obtained for a new study - to find out what happens to those with a diagnosis of an Autism Spectrum Disorder (ASD) in adulthood. We are a team of researchers at King's College London and you have been chosen to be invited to participate in this study although you are under no obligation to take part. This research is important because we know that an ASD is a lifelong disorder, yet we know very little about the service use and needs (if any) of adults diagnosed with an ASD.

We are therefore inviting adults who have a diagnosis of an ASD to take part in this study (a letter about this study has also been sent to your parent). This is because it is sometimes difficult for people with an ASD to judge their own social and communication difficulties so it is important for us to ask someone who knows you well.

The project is part of a programme to develop more effective services and treatments for adults with an ASD that has been funded by the National Institute of Health Research (NIHR); who are the major funding body for National Health Service (NHS) research in the UK. The project brings together a team of researchers from the Institute of Psychiatry, King's College London (KCL) and the London School of Economics (LSE).

Please find enclosed a STUDY FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that may turn up in the future.

If you would prefer not to be contacted by the research team please return the enclosed STUDY FORM in the freepost envelope by [four day's date], stating that you do not wish to be contacted. If we have not heard from you by this time, a member of the research team will

ring you to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews.

### **Background to the study**

This study came about because there are currently very limited resources to help people who have persistent problems with an ASD once they reach adulthood. Although we know that some people with an ASD may feel that their ASD has improved since they were children this is not always the case, and it is currently very difficult for adults with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adulthood but may find that they still struggle at work or in their social relationships due to the persistence of some problems related to their ASD. We are therefore interested in families with a wide range of experiences related to ASD and services.

We wish to find out more about the way that people diagnosed with an ASD are coping as adults - whether problems with the ASD have improved or are being successfully managed, or whether some problems related to the ASD have continued. Where there are continued problems we wish to know whether people are receiving the support and treatment that they need for any problems related to the ASD. We are also interested in finding out how the ASD may impact on the well-being of others (such as parents).

### **What does the project involve?**

The main part of the research involves an interview with you and your parent. With your permission, the focus of the questionnaires will be on your use of health and social services and level of need (if any). If there are continued problems with the ASD (or problems related to the ASD) that involves your parent supporting you in any way, we would also like to ask about the impact of your condition on your parent's well-being, employment situation and health. We understand that some adults may not have the capacity to fully understand what this study involves. Therefore, we may need to assess comprehension before we proceed with any interviews.

### **How can I find out more about this study?**

Please find enclosed an information sheet which explains more about the study. If you have any further enquiries, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Valerie D'Astous, NIHR researcher and PhD student  
Hannah Hayward, NIHR researcher  
Dr Karen Glaser, Senior Lecturer in Gerontology  
Prof Philip Asherson, Professor in Molecular Psychiatry

## Stage One: Adults with ASD information sheet



Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of Child  
and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous, Ms. Hannah Hayward*

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### Adult with ASD Information Sheet

21.05.13 v5.0

Information sheet for the study of the service use and needs among adults with an Autism Spectrum Disorder (ASD).

**Please read the following information before you decide  
whether to participate in this research**

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this. *What is the purpose of the study?*

The aim of this study is to investigate service use, needs and associated outcomes among those who have received a diagnosis of an ASD and who are now adults. This will involve a questionnaire based interview with you.

- ASDs have largely been regarded as childhood disorders despite growing evidence that symptoms continue into adulthood. Thus, few studies into the service use and needs of adults with this disorder have been conducted.

#### **Why have you been chosen?**

We are inviting people (and their families) who have a diagnosis of an ASD. We will be examining patterns of service use and needs and will look at how these change during adulthood. We are also interested in investigating the impact of these changes on your, and with your consent, your parent's well-being.

#### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you

are still free to stop your participation at any time and to have any research data withdrawn without giving any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

### **What will I have to do if I take part?**

At a time convenient for you a researcher will interview you at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed). The interviewer may need to assess whether you understand what the study is about and what taking part involves before proceeding with the interview. We will ask some questions about your level of need (from your perspective) as well as some brief questions on your moods, alcohol and drug use and any police contact. It would be helpful if we could do this in a private area to ensure confidentiality. If you prefer to have your parent or partner present this is fine too.

The interview with you and your parent is in three parts. The first part consists of answering some questions with you about your ASD symptoms, your daily life (such as employment, study etc.) and your level of needs as well as about any other psychological symptoms you may have (from their perspective). This is because it is sometimes difficult for people with an ASD to judge their own social and communication difficulties so it is important for us to ask someone who knows you well, such as one of your parents to answer some questions about you from their perspective

In the second part of the interview we will ask questions about your service use, daily life, current employment situation, and health. Following this, we would like to ask you and your parent about services you have used in the past few months and about your experiences of adult services.

As a thank you for your time, you will be given a £25 gift voucher at the interview.

### **What are the possible benefits of taking part?**

There are no immediate clinical benefits to taking part. However, participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform service use during adulthood among those with an ASD.

### **What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you and your parent/partner will be donating around an hour or so of your time to take part. It is possible that you may find answering some of the questions distressing. If so, the researchers can provide you with the contact details of appropriate organisations. This is unlikely but if it were to occur the interview could be terminated at any time.

### **Confidentiality**

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

### **What if something goes wrong?**

We don't envisage any major risk associated with taking part in this study. In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

**Consent**

If in the unlikely event that, after giving informed consent, you were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of. Before we obtain your consent, we would like to make sure you fully understand what the study is about and what it involves. If you do not fully understand what this study is about, and what taking part in the study involves, we will ask your parent to nominate a relative, close family friend or other appropriate person to act on your behalf in making a decision about whether you are able to take part.

**What will happen to the results of the research study?**

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for people with an ASD. A report of the study findings can be sent to you once the research has been completed. The results of the study will be represented in scientific journals and research theses, and they will be used to inform the development of service provision.

**Who is organising and funding the research?**

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

**Who has reviewed the study?**

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

**Future developments at Kings**

We would like to be able to contact you with details of further research projects concerning people with an ASD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

**Contact for further information:**

Please ask if there is anything you do not understand or if you would like more information.

Valerie D'Astous, King's College London, The Strand, London, WC2R 2LS

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Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)

Hanna Hayward, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

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Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London, SE5 8AF.

Tel: 020 7848 0078

E-mail: [Philip.Asherson@kcl.ac.uk](mailto:Philip.Asherson@kcl.ac.uk)

## Stage One: Study form



Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of  
Child and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Valerie D'Astous*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422*

Study form 06.10.14 v6.0

Study Reference Number: 09/H0807/71

[DATE]

Study Form Service Use and Needs v6.0

☐ I/ We have read the information provided and would be happy for a researcher to  
phone and discuss this study ☐

☐ I/We have read the information provide and do not wish to be contacted about this  
study ☐

(Please send back this form in the freepost envelope provided)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Participant Print name:

\_\_\_\_\_  
Parents Print name:

Address: Please provide details so that we can identify who you are for our records.



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Telephone: \_\_\_\_\_

Mobile number: \_\_\_\_\_

Email address: \_\_\_\_\_

**We are interested in any siblings that you have (whether or not they have been diagnosed with an ASD and regardless of whether they are full or half siblings). Please provide details of all your siblings and whether or not they have been diagnosed with an Autism Spectrum Disorder (ASD).**

Sibling's name	Gender	D.O.B	Diagnosis (ASD if applicable)	Medication (if applicable)
----------------	--------	-------	-------------------------------	----------------------------

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Do they all live with you? If not, would you be willing to provide us with contact details? If so, please fill in below.

Name:

Address:

Telephone number:

Mobile number:

Email address:

Does he/she live with a partner?

Name:

Address:

Telephone number:

Mobile number:

Email address:

Does he/she live with a partner?

Name:

Address:

Telephone number:

Mobile number:

Email address:

Does he/she live with a partner?

**Please return in freepost envelope provided.**

## Stage Two: Adult with ASD invitation letter



Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of  
Child and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous, Ms. Hannah  
Hayward*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)*

*Tel: 07423168422*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)*

*Tel: 02078485359; Tel. 07895267597*

### **Adult with ASD Invitation Letter**

**21.05.13 v1.0**

Date

Address

Dear Mrs./Mr.

You took part in the first stage of a study on service use and needs of adults with autism. We would like to thank you for your earlier participation in this project.

We are now conducting the second stage – to find out about future support and service needs for adults with an ASD. We are a team of researchers at King's College London and you and your family have been chosen to be invited to participate in this study although you are under no obligation to take part. This research is important because we know that an ASD is a lifelong disorder, yet we know very little about the long term care and support needs of adults diagnosed with an ASD.

Please find enclosed a STUDY FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that may turn up in the future.

If you would prefer not to be contacted by the research team please return the enclosed STUDY FORM in the freepost envelope by [four day's date], stating that you do not wish to be contacted. If we have not heard from you by this time, a member of the research team will ring you to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews.

### **Background to the study**

This study came about because there are currently very limited resources to help people who have persistent problems with an ASD once they reach adulthood. Although we know that some people with an ASD may feel that their ASD has improved since they were children this is not always the case, and it is currently very difficult for adults with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adulthood but may find that they still struggle at work or in their social relationships

due to the persistence of some problems related to their ASD. We are therefore interested in families with a wide range of experiences related to ASD.

We wish to find out more about the plans that adults with an ASD have for the future and in particular what support and services you may need. The needs of adults with an ASD vary considerably and therefore so will future planning. As an adult with an ASD we are interested in finding out how you see your future support and service needs, family roles and relationships, and any long-term care plans. We are also interested in finding out how your parent and at least one of your siblings sees the future (in terms of your support and service needs, family roles and relationships, and any long-term care plans).

**What does the project involve?**

The main part of the research involves a brief interview with you about the future support and services that you may need, family roles and relationships, and any long term care plans you may have considered.

**How can I find out more about this study?**

Please find enclosed an information sheet which explains more about the study. If you have any further enquiries, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Valerie D'Astous, NIHR researcher and PhD student  
Hannah Hayward, NIHR researcher  
Dr Karen Glaser, Senior Lecturer in Gerontology  
Prof Philip Asherson, Professor in Molecular Psychiatry

## Stage Two: Adults with ASD information Sheet



Institute of Psychiatry  
Social, Genetic and Developmental Psychiatry  
Centre and Department of Child and Adolescent  
Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser, Ms.  
Hannah Hayward, Ms. Valerie D'Astous*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)  
Tel: 02078485359; Tel. 07895267597  
Email: [Valerie.Dastous@kcl.ac.uk](mailto:Valerie.Dastous@kcl.ac.uk)  
Tel: 07423168422*

### **Adult with ASD Information Sheet**

**21.05.13 v1.0**

Information sheet for the study of future service and support needs of adults with an ASD post parental care.

**Please read the following information before you decide  
whether to participate in this research**

You, your parent and sibling are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

#### **What is the purpose of the study?**

The aim of this study is to investigate future support and service needs among adults who have a diagnosis of an ASD. This will involve a brief interview with you, your parent and sibling.

ASDs have largely been regarded as childhood disorders despite growing evidence that symptoms continue into adulthood. Thus, few studies into the future support and service needs of adults with this disorder have been conducted. Moreover, despite the importance of the need for continuity of health and social services for the wellbeing of adults with an ASD in adulthood and planning for their future support, these issues have received little investigation.

#### **Why have you been chosen?**

We are inviting adults who have a diagnosis of an ASD (and their families). As an adult with an ASD you are being invited to participate. We will be investigating how you see your future support and service needs, family roles and relationships, and what considerations (if any) you and your family have given to planning for long-term care.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation at any time and to have any research data withdrawn without giving any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

**What will I have to do if I take part?**

At a time convenient for you a researcher will interview you, your brother/sister and your parent (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed).

The interview should take approximately 30 minutes and has a flexible structure. It consists of questions about your perception of the support and services you anticipate you will need in the future to maintain your welfare, family roles and relationships, and what caregiving role (if any) you see for your sibling.

**What are the possible benefits of taking part?**

There are no immediate clinical benefits to taking part. However, participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform future service and support needs for adults with an ASD.

**What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you will be donating around half an hour or so to take part. It is possible that you may find answering some of the questions distressing. If so, the researchers can provide you with the contact details of appropriate organisations. This is unlikely but if it were to occur the interview could be terminated at any time.

**Confidentiality**

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

**What if something goes wrong?**

We don't envisage any major risk associated with taking part in this study. In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

**Consent**

If in the unlikely event that, after giving informed consent, you were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of. Before we obtain your consent, we would like to make sure you fully understand what the study is about and what it involves. If you do not fully understand what this study is about, and what taking part in the study involves, we will ask your parent to nominate a relative, close family friend or other appropriate person to act on your behalf in making a decision about whether you are able to take part.

**What will happen to the results of the research study?**

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform

health service provision and the development of services for ASD. A report of the study findings can be sent to you once the research has been completed. The results of the study will be represented in scientific journals and research theses, and they will be used to inform the development of service provision and a future care plan strategy for adults with ASD.

**Who is organising and funding the research?**

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

**Who has reviewed the study?**

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

**Future developments at Kings**

We would like to be able to contact you with details of further research projects concerning young people with an ASD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

**Contact for further information:**

Please ask if there is anything you do not understand or if you would like more information.

Valerie D'Astous, King's College London, The Strand, London, WC2R 2LS

Tel: 0742 316 8422

Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)

Hanna Hayward, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

Tel: 0207 848 5359

Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)

Dr Karen Glaser, King's College London, The Strand, London, WC2R 2LS

Tel: 020 7848 2554

E-mail: [Karen.Glaser@kcl.ac.uk](mailto:Karen.Glaser@kcl.ac.uk)

Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London, SE5 8AF.

Tel: 020 7848 0078

E-mail: [Philip.Asherson@kcl.ac.uk](mailto:Philip.Asherson@kcl.ac.uk)

## Stage Two: Study form



Institute of Psychiatry  
Social, Genetic and Developmental Psychiatry  
Centre and Department of Child and  
Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser, Ms.  
Valerie D'Astous, Ms. Hannah Hayward*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)*

*Tel: 07423168422*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)*

*Tel: 02078485359; Tel. 07895267597*

**Study form 21.05.2013 v1.0**

Study Reference Number: 09/H0807/71

[DATE]

### **Study Form Future Service and Support Needs v1.0**

☐ I/ We have read the information provided and would be happy for a researcher to  
phone and discuss this study ☐

☐ I/We have read the information provide and do not wish to be contacted about this  
study ☐

**(Please send back this form in the freepost envelope provided)**

Signature \_\_\_\_\_

Signature \_\_\_\_\_

Print name \_\_\_\_\_

Print name \_\_\_\_\_



Address: Please provide details so that we can identify who you are for our records.

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Telephone: \_\_\_\_\_

Mobile number: \_\_\_\_\_

Email address: \_\_\_\_\_

**Please return in freepost envelope provided.**

## Stage Two: Parent Invitation letter



Institute of Psychiatry

Social, Genetic and Developmental  
Psychiatry Centre and Department of  
Child and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous, Ms. Hannah  
Hayward*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)*

*Tel: 07423168422*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)*

*Tel: 02078485359; Tel. 07895267597*

### **Parent Invitation Letter**

**21.05.13 v1.0**

Date

Address

Dear Mrs./Mr.

You and your family took part in an NIHR study on service use and needs lead by Professor Philip Asherson. We would like to thank you for your earlier participation in this project.

We are now conducting a new study – to find out about future support and service needs for adults with an ASD. We are a team of researchers at King's College London and you and your family have been chosen to be invited to participate in this study although you are under no obligation to take part. This research is important because we know that an ASD is a lifelong disorder, yet we know very little about the long term care and support needs of adults diagnosed with an ASD.

Please find enclosed a STUDY FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that may turn up in the future.

If you would prefer not to be contacted by the research team please return the enclosed STUDY FORM in the freepost envelope by [four day's date], stating that you do not wish to be contacted. If we have not heard from you by this time, a member of the research team will ring you to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews.

### **Background to the study**

This study came about because there are currently very limited resources to help people who have persistent problems with an ASD once they reach adulthood. Although we know that some people with an ASD may feel that their ASD has improved since they were children this is not always the case, and it is currently very difficult for adults with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adulthood but may find that they still struggle at work or in their social relationships

due to the persistence of some problems related to their ASD. We are therefore interested in families with a wide range of experiences related to ASD.

We wish to find out more about the plans that families and adults with an ASD have for the future and in particular what support and services they may need. The needs of adults with an ASD vary considerably and therefore so will future care planning. As a parent and a care provider for your child with an ASD, you are the 'expert' and know your child and their needs better than anyone. Consequently, you are perhaps in the best position to decide on appropriate plans for their future. We are also interested in finding out how your adult child with an ASD and at least one of their siblings sees the future (support and service needs, family roles and relationships and long-term care plans).

**What does the project involve?**

The main part of the research involves a brief interview with you about the future support and services that your adult child with an ASD may need, family roles and relationships, your caregiving role and any long-term care plans you may have considered. We are also interested in understanding what if anything has helped you or hindered you from making long term care plans for your adult child with an ASD.

**How can I find out more about this study?**

Please find enclosed an information sheet which explains more about the study. If you have any further enquiries, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Valerie D'Astous, NIHR researcher and PhD student  
Hannah Hayward, NIHR researcher  
Dr Karen Glaser, Senior Lecturer in Gerontology  
Prof Philip Asherson, Professor in Molecular Psychiatry

## Stage Two: Parent information sheet



University of London

Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of Child  
and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous, Ms. Hannah Hayward*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422  
Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)  
Tel: 02078485359; Tel. 07895267597*

### Parent Information Sheet

21.05.13 v5.0

Information sheet for the study of service use and needs among adults with an Autism Spectrum Disorder (ASD).

**Please read the following information before you decide  
whether to participate in this research**

You and your son/daughter are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

### **What is the purpose of the study?**

The aim of this study is to investigate service use, needs and associated outcomes among those who have received a diagnosis of an ASD and who are now adults. This will involve a questionnaire based interview with you and where possible, with your son/daughter.

- ASDs have largely been regarded as childhood disorders despite growing evidence that symptoms continue into adulthood. Thus, few studies into the service use and needs of adults with this disorder have been conducted.

### **Why have you been chosen?**

We are inviting families who have an adult son/daughter with a diagnosis of an ASD. We will be examining patterns of service use and needs and will look at how these change during adulthood. We are also interested in investigating the impact of these changes on your, as well as your child's, well-being.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation at any time and to have research data relating to you withdrawn without giving any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

**What will I have to do if I take part?**

At a time convenient for you and your son/daughter (with their consent), the researcher will arrange to interview you at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed). The interviewer may need to assess whether your son/daughter understands what the study is about and what taking part involves before proceeding with the interview.

The interview will take approximately one hour and is designed to be flexible to meet the needs of both you and your son/daughter. Should your son/daughter wish and be able to answer some of the questions alone we would be grateful if we could ask these questions in a private area with your son/daughter (for confidentiality reasons). We will ask your son/daughter about their level of need and their moods (from their perspective) and we will also ask a brief series of questions about their alcohol and drug use and any police contact.

The interview with you is in three parts and begins by asking you to complete questions about your son/daughter. We are asking you to answer questions about your son/daughter from your perspective as it is sometimes difficult for people with an ASD to answer questions about themselves and it is important for us to ask someone who knows your son or daughter well, such as yourself, to answer such questions. We will ask you about your son or daughter's ASD symptoms and about their daily life (such as employment, study etc.). We would also like to ask you about your child's level of need as best as you can (from your perspective), and about any other psychological symptoms they may have. We will also ask a brief series of questions about your son/daughter's moods, alcohol and drug use, and any police contact.

In the second part of the interview we would like to ask you to answer a few questions together with your son/daughter (if possible) about the services she/he has used in the past few months and about his/her experiences of adult services.

**What are the possible benefits of taking part?**

There are no immediate clinical benefits to taking part. However, participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform service use during adulthood among those with an ASD.

**What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you and your son/daughter will be donating around an hour or so of your time to take part. It is possible that you may find answering some of the questions distressing. If so, the researchers can provide you with the contact details of appropriate organisations. This is unlikely but if it were to occur the interview could be terminated at any time.

**Confidentiality**

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

**What if something goes wrong?**

We don't envisage any major risks associated with taking part in this study. In the event of you or your son/daughter suffering any adverse effects as a consequence compensation will be made through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

### **Consent**

If in the unlikely event that, after giving informed consent, either you or your son/daughter were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of. Before we obtain consent, we would like to make sure you and your son/daughter fully understand what the study is about and what it involves. If your son/daughter is not able to understand what the study is about and what it involves, we will ask you to nominate a relative, close family friend or other appropriate person to act on your son or daughter's behalf in making a decision about whether they are able to take part.

### **What will happen to the results of the research study?**

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for ASD. A report of the study findings can be sent to you once the research has been completed. The results of the study will be represented in scientific journals and research theses, and will be used to inform the development of service provision.

### **Who is organising and funding the research?**

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

### **Who has reviewed the study?**

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

### **Future developments at Kings**

We would like to be able to contact you with details of further research projects concerning young people with an ASD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

### **Contact for further information:**

Please ask if there is anything you do not understand or if you would like more information.

Valerie D'Astous, King's College London, The Strand, London, WC2R 2LS  
Tel: 0742 316 8422 Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)

Hanna Hayward, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF  
Tel: 0207 848 5359 Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)

Dr Karen Glaser, King's College London, The Strand, London, WC2R 2LS  
Tel: 020 7848 2554 E-mail: [Karen.Glaser@kcl.ac.uk](mailto:Karen.Glaser@kcl.ac.uk)

Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London, SE5 8AF.  
Tel: 020 7848 0078 E-mail: [Philip.Asherson@kcl.ac.uk](mailto:Philip.Asherson@kcl.ac.uk)

## Stage Two: Sibling invitation letter



Institute of Psychiatry

Social, Genetic and Developmental  
Psychiatry Centre and Department of Child  
and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Hannah Hayward, Ms. Valerie D'Astous*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)  
Tel: 02078485359; Tel. 07895267597  
Email: [Valerie.Dastous@kcl.ac.uk](mailto:Valerie.Dastous@kcl.ac.uk)  
Tel: 07423168422*

Date

Address

Dear Mrs./Mr.

### **Sibling Invitation Letter** **21.05.13 v1.0**

We are a team of researchers at King's College London who are interested in finding out about the long term care and support needs of adults with an Autism Spectrum Disorder (ASD). You, your sibling with an ASD and your parent have been chosen to be invited to participate in this study although you are under no obligation to do so. This research is important because we know that having an ASD is a lifelong disorder yet we know very little about the long-term care and support needs (if any) of adults diagnosed with an ASD.

We are therefore inviting family members who have an adult brother or sister with a diagnosis of an ASD to take part in this study.

Please find enclosed a STUDY FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that may turn up in the future.

If you would prefer not to be contacted by the research team please return the enclosed STUDY FORM in the freepost envelope by [four day's date], stating that you do not wish to be contacted. If we have not heard from you by this time, a member of the research team will ring you to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews.

### **Background to the study**

This study came about because there are currently very limited resources to help people who have persistent problems with an ASD once they reach adulthood. Although we know that some people with an ASD may feel that their ASD has improved since they were children this is not always the case, and it is currently very difficult for adults with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adulthood but may find that they still struggle at work or in their

social relationships due to the persistence of some problems related to their ASD. We are therefore interested in families with a wide range of experiences related to ASD.

We wish to find out more about the plans that families and adults with an ASD have for the future and in particular what support and services they may need. The needs of adults with an ASD vary considerably and therefore so will future care planning. As a family member of an adult with an ASD, we are interested in finding out how you see your sibling's future in terms of their support and service needs, family roles and relationships and long-term care plans.

**What does the project involve?**

The main part of the research involves a brief interview with you about the future support and services that your adult brother/sister with an ASD may need, family roles and relationships, and any long term care plans you and your family may have considered.

**How can I find out more about this study?**

Please find enclosed an information sheet which explains more about the study. If you have any further enquiries, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Valerie D'Astous, NIHR researcher and PhD student  
Hannah Hayward, NIHR researcher  
Dr Karen Glaser, Senior Lecturer in Gerontology  
Prof Philip Asherson, Professor in Molecular Psychiatry



## Stage Two: Sibling information sheet



Institute of Psychiatry  
Social, Genetic and Developmental Psychiatry  
Centre and Department of Child and Adolescent  
Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser, Ms.  
Hannah Hayward, Ms. Valerie D'Astous*

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Tel: 02078485359; Tel. 07895267597  
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Tel: 07423168422*

### **Sibling Information Sheet**

**21.05.13 v1.0**

Information sheet for the study of future service and support needs of adults with an ASD post parental care.

**Please read the following information before you decide  
whether to participate in this research**

You, your parent and sibling with an ASD are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

What is the purpose of the study?

The aim of this study is to investigate future support and service needs among adults who have a diagnosis of an ASD. This will involve a brief interview with you, your parent and your adult sibling with an ASD.

- ASDs have largely been regarded as childhood disorders despite growing evidence that symptoms continue into adulthood. Thus, few studies into the service use and needs of adults with this disorder have been conducted. Moreover, despite the importance of the need for continuity of health and social services for the wellbeing of adults with an ASD in adulthood and planning for their future care, these issues have received little investigation.

**Why have you been chosen?**

We are inviting families who have an adult family member who has a diagnosis of an ASD (and their families). As a sibling of an adult brother or sister with an ASD you are being invited to participate. We are interested in investigating how you see your brother/sister's future service and support needs, family roles and relationships, and what considerations (if any) you and your family have given to planning for their long term care.

### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation at any time and to have any research data withdrawn without giving any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

### **What will I have to do if I take part?**

At a time convenient for you a researcher will interview you, your adult brother or sister with an ASD, and your parent at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed).

The interview should take approximately 30 minutes and has a flexible structure. It consists of questions about your perception of the services and supports you anticipate your brother/sister may need in the future to maintain his/her welfare, family roles and relationships, your caregiving role (if any) and any long-term care plans (if any) you and your family have/see for your sibling.

### **What are the possible benefits of taking part?**

There are no immediate clinical benefits to taking part. However, participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform future service and support needs for adults with ASD.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you will be donating around half an hour or so to take part. It is possible that you may find answering some of the questions distressing. If so, the researchers can provide you with the contact details of appropriate organisations. This is unlikely but if it were to occur the interview could be terminated at any time.

### **Confidentiality**

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

### **What if something goes wrong?**

We don't envisage any major risk associated with taking part in this study. In the event of you suffering any adverse effects as a consequence of your participation in this study, you will be compensated through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

### **Consent**

If in the unlikely event that, after giving informed consent, you were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of. Before we obtain your consent, we would like to make sure you fully understand what the study is about and what it involves.

**What will happen to the results of the research study?**

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for ASD. A report of the study findings can be sent to you once the research has been completed. The results of the study will be represented in scientific journals and research theses, and they will be used to inform the development of service provision and a future care plan strategy for adults with ASD.

**Who is organising and funding the research?**

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

**Who has reviewed the study?**

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

**Future developments at Kings**

We would like to be able to contact you with details of further research projects concerning young people with an ASD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

**Contact for further information:**

Please ask if there is anything you do not understand or if you would like more information.

Valerie D'Astous, King's College London, The Strand, London, WC2R 2LS

Tel: 07423168422

Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)

Hanna Hayward, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF

Tel: 0207 848 5359

Email [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)

Dr Karen Glaser, King's College London, The Strand, London, WC2R 2LS

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Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London, SE5 8AF.

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## Stage Two: Partner invitation letter



Institute of Psychiatry  
Social, Genetic and Developmental  
Psychiatry Centre and Department of Child  
and Adolescent Psychiatry

*Prof. Philip Asherson, Dr Karen Glaser,  
Ms. Valerie D'Astous*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422*

Date  
Address  
Dear Mrs./Mr.

### **Stage 2 Partner Invitation Letter v1.0** **21.05.13 v1.0**

We are a team of researchers at King's College London who are interested in finding out about the long term care and support needs of adults with an Autism Spectrum Disorder (ASD). You, your partner with an ASD have been chosen to be invited to participate in this study although you are under no obligation to do so. This research is important because we know that having an ASD is a lifelong disorder yet we know very little about the long-term care and support needs (if any) of adults diagnosed with an ASD.

We are therefore inviting family members who have partner with a diagnosis of an ASD to take part in this study.

Please find enclosed a STUDY FORM, which we would greatly appreciate if you could fill in and return to us. This will enable us to keep you informed about progress with this and other projects that may turn up in the future.

If you would prefer not to be contacted by the research team please return the enclosed STUDY FORM in the freepost envelope by [four day's date], stating that you do not wish to be contacted. If we have not heard from you by this time, a member of the research team will ring you to discuss the project. If you would like to take part they will arrange a home visit (or a visit to our centre if you prefer) to conduct the interviews.

#### **Background to the study**

This study came about because there are currently very limited resources to help people who have persistent problems with an ASD once they reach adulthood. Although we know that some people with an ASD may feel that their ASD has improved since they were children this is not always the case, and it is currently very difficult for adults with continued problems to get the help they need. In some cases people may feel that they no longer need help once they reach adulthood but may find that they still struggle at work or in their social relationships due to the persistence of some problems related to their ASD. We are therefore interested in families with a wide range of experiences related to ASD.

We wish to find out more about the plans that families and adults with an ASD have for the future and in particular what support and services they may need. The needs of adults with an ASD vary considerably and therefore so will future care planning. As a family member of an adult with an ASD, we are interested in finding out how you see your partner's future in term of their support and service needs, family roles and relationships and long-term care plans.

**What does the project involve?**

The main part of the research involves a brief interview with you about the future support and services that your partner with an ASD may need, family roles and relationships, and any long term care plans you and your family may have considered.

**How can I find out more about this study?**

Please find enclosed an information sheet which explains more about the study. If you have any further enquiries, please do not hesitate to contact us.

Many thanks for taking the time to read this letter.

Yours sincerely,

Valerie D'Astous, NIHR researcher and PhD student  
Dr Karen Glaser, Senior Lecturer in Gerontology  
Prof Philip Asherson, Professor in Molecular Psychiatry

## Stage Two: Partner information sheet



*Institute of Psychiatry Social, Genetic and  
Developmental Psychiatry Centre and  
Department of Child and Adolescent Psychiatry*

*Prof. Philip Asherson, Dr Karen Glaser, Ms.  
Valerie D'Astous*

*Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422*

### **Stage 2 Partner Information Sheet**

**21.05.13 v1.0**

Information sheet for the study of future service and support needs of adults with an ASD post parental care.

**Please read the following information before you decide  
whether to participate in this research**

You, your partner with an ASD are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. **Your participation in this study is completely voluntary.**

Thank you for reading this.

#### **What is the purpose of the study?**

The aim of this study is to investigate future support and service needs among adults who have a diagnosis of an ASD. This will involve an interview with you and your partner with an ASD. The research forms part of a doctoral degree and the student will be involved in the analysis and collection of data.

- ASDs have largely been regarded as childhood disorders despite growing evidence that symptoms continue into adulthood. Thus, few studies into the future service use and needs of adults with this disorder have been conducted. Moreover, despite the importance of the need for continuity of health and social services for the wellbeing of adults with an ASD in adulthood and planning for their future support, these issues have received little investigation.

#### **Why have you been chosen?**

We are inviting families who have an adult with a diagnosis of an ASD. We are interested in investigating the future service and support needs of your partner, family roles and relationships and what considerations (if any) you have given to planning for their long-term support.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are still free to stop your participation at any time and to have research data relating to you withdrawn without giving any reason. Please note that once analysis of the anonymised data is under way it will not be possible to have data withdrawn.

**What will I have to do if I take part?**

At a time convenient for you and your partner with an ASD the researcher will arrange to interview you at home (or at the Institute of Psychiatry if you prefer, your travel expenses will be reimbursed). The interviewer may need to assess whether your partner with an ASD understands what the study is about and what taking part involves before proceeding with his/her interview.

The interview should take approximately 30 minutes and has a flexible structure. It consists of questions about your perception of the services and supports that you anticipate your partner with an ASD may need in the future to maintain his/her welfare, family roles and relationships, your caregiving role, and any long-term care plans (if any) you see for your partner.

**What are the possible benefits of taking part?**

There are no immediate clinical benefits to taking part. However, participating in research projects is often a rewarding and interesting experience. The information we get from the study will help to better inform future service and support needs in adulthood for adults with ASD.

**What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks in taking part in the study. The main disadvantage to taking part in the study is that you will be donating around a half an hour or so of your time to take part. It is possible that you may find answering some of the questions distressing. If so, the researchers can provide you with the contact details of appropriate organisations. This is unlikely but if it were to occur the interview could be terminated at any time.

**Confidentiality**

All personal information is regarded as strictly confidential and will be held securely until the research is completed. Your participation is voluntary. If you change your mind, you are free to stop your participation and to have your data withdrawn without giving any reason. All data for analysis will be anonymised.

**What if something goes wrong?**

We don't envisage any major risks associated with taking part in this study. In the event of you or your partner suffering any adverse effects as a consequence compensation will be made through the King's College London 'No Fault' Compensation Scheme. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any clinical trial.

**Consent**

If in the unlikely event that, after giving informed consent, either you or your partner were to lose capacity once the study had begun, participation would be terminated immediately and any identifiable data would be either anonymised or disposed of. Before we obtain consent, we would like to make sure you and your partner fully understand what the study is about and what it involves. If your partner is not able to understand what the study is about and what it involves, we will ask you to nominate a relative, close family friend or other appropriate person to act on your partner's behalf in making a decision about whether they are able to take part.

**What will happen to the results of the research study?**

This research will be analysed by researchers at the Institute of Psychiatry, King's College London (KCL), and the London School of Economics (LSE). The results will be used to inform health service provision and the development of services for ASD. A report of the study findings can be sent to you once the research has been completed. The results of the study will be published in scientific journals and doctoral theses, and will be used to inform the development of service provision and a future care plan strategy for adults with ASD.

**Who is organising and funding the research?**

The National Institute for Health Research (NIHR) funds this research. This is government funding aimed at improving clinical diagnosis, treatment and health provision in the United Kingdom.

**Who has reviewed the study?**

The study has been subject to review by expert referees for the National Institute for Health Research. The NHS Research Ethics Committee has granted ethical approval.

**Future developments at Kings**

We would like to be able to contact you with details of further research projects concerning adults with an ASD at the Institute of Psychiatry in the future. However, you are under no obligation to agree to be contacted about future participation.

**Contact for further information:**

Please ask if there is anything you do not understand or if you would like more information.

Valerie D'Astous, King's College London, The Strand, London, WC2R 2LS

Tel: 07423168422

Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)

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Professor Philip Asherson, MRC Social Genetic and Developmental Psychiatry, The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London, SE5 8AF.

Tel: 020 7848 0078

E-mail: [Philip.Asherson@kcl.ac.uk](mailto:Philip.Asherson@kcl.ac.uk)



## Appendix C: Consent forms

### Stage One: Consent form



*Institute of Psychiatry  
Social, Genetic and Developmental Psychiatry Centre and  
Department of Child and Adolescent Psychiatry*

*Prof. Philip Asherson, Dr Karen Glaser, Ms. Hannah Hayward,  
Ms. Valerie D'Astous*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)  
Tel: 02078485359; Tel. 07895267597  
Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422*

### Consent Form v5.0 21.05.13

**Study Title: The study of service use and needs among adults with an Autism Spectrum Disorder (ASD).**

Please tick boxes **n** this research, please read and sign the form below

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 1. I have read the information sheet, and I have been given a copy. I was given the opportunity to contact a member of the research team to ask questions.  | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 2. I consent that the information I provide about myself and my family members can be stored at the Institute of Psychiatry indefinitely until the research is completed. Any future work and any extension of the project will be subject to review by a research ethics committee | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 3. I understand that I am free to stop my participation in this study at any time and that I can ask to have my data withdrawn without giving any reason.   | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 4. I consent to the input of anonymous data obtained from the information gathered about me into a computer, to be used for statistical analysis and research.  | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 5. I consent to be contacted about future ASD research  | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 6. I would like to be sent information on the outcome of the study.   | <input type="checkbox"/> YES | <input type="checkbox"/> NO |

.....  
Name of participant                      Date                      Signature

I have explained the study and answered any questions from the participant honestly and fully

.....  
Name of researcher                      Date                      Signature

Contact details for research team: Valerie D'Astous, Hannah Hayward, and The Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF.  
E-mail: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk); [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk) Tel: 02078485359

## Stage Two: Consent form



*Institute of Psychiatry  
Social, Genetic and Developmental Psychiatry  
Centre and Department of Child and  
Adolescent Psychiatry*

*Prof. Philip Asherson, Dr Karen Glaser, Ms.  
Hannah Hayward, Ms. Valerie D'Astous*

*Email: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk)  
Tel: 02078485359; Tel. 07895267597  
Email: [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk)  
Tel: 07423168422*

### Consent Form v1.0 21.05.13

Study Title: The future service and support needs for adults with ASD post parental care.

Please tick boxes in this research, please read and sign the form below

- |   |                              |                              |
|---|------------------------------|------------------------------|
| 1. I have read the information sheet, and I have been given a copy. I was given the opportunity to contact a member of the research team to ask questions.  | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |
| 2. I consent that the information I provide about myself and my family members can be stored at the Institute of Psychiatry indefinitely until the research is completed. Any future work and any extension of the project will be subject to review by a research ethics committee | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |
| 3. I understand that I am free to stop my participation in this study at any time and that I can ask to have my data withdrawn without giving any reason.   | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |
| 4. I consent to the input of anonymous data obtained from the information gathered about me into a computer, to be used for statistical analysis and research.  | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |
| 5. I consent to having this interview recorded to accurately capture what I say.  | <input type="checkbox"/> YES | <input type="checkbox"/> YES |
| 6. I consent to be contacted about future ASD research  | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |
| 7. I would like to be sent information on the outcome of the study.   | <input type="checkbox"/> YES | <input type="checkbox"/> NO  |

.....

.....

.....

I have explained the study and answered any questions from the participant honestly and fully

.....

.....

.....

**Contact details for research team:** Valerie D'Astous, Hannah Hayward, and the Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF.

E-mail: [Hannah.Hayward@kcl.ac.uk](mailto:Hannah.Hayward@kcl.ac.uk); [Valerie.D'astous@kcl.ac.uk](mailto:Valerie.D'astous@kcl.ac.uk) Tel: 02078485359

## Appendix D: Quantitative research instrument

### Client service receipt inventory (CSRI)

ID			-				-				
----	--	--	---	--	--	--	---	--	--	--	--



## **ADULT ASD SERVICE USE INTERVIEW**

### **BOOKLET**

Name of participant: \_\_\_\_\_

Date of birth of participant: \_\_\_\_\_

Gender: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Name of interviewer: \_\_\_\_\_

*In this interview we are looking at the service use and needs of people with an ASD and the impact of having this disorder. We know these factors are important and we would like to know how they affect you.*

## First please can I check a few things with you

### 1. What would you say is your ethnic group?

- |                                       |   |  |
|---------------------------------------|---|--|
| White- UK <input type="checkbox"/>    | Asian- Middle East <input type="checkbox"/> | Asian – Oriental <input type="checkbox"/>        |
| Asian- Other <input type="checkbox"/> | Black- Caribbean <input type="checkbox"/>   | Black- African <input type="checkbox"/>          |
| Black- Other <input type="checkbox"/> | White- Irish <input type="checkbox"/>       | I do not wish to answer <input type="checkbox"/> |
| White- Other <input type="checkbox"/> | Other <input type="checkbox"/>              |  |

### 2. What is your current marital status?

- |  |                                  |  |
|--|----------------------------------|--|
| Never married <input type="checkbox"/> | Married <input type="checkbox"/> | Separated or divorced <input type="checkbox"/> |
| Cohabiting <input type="checkbox"/>    | Widowed <input type="checkbox"/> |  |

### 3. Have you ever...?    Been married ☐    Cohabited ☐    Divorced ☐

### 4. IF NOT CURRENTLY A STUDENT, What is the highest educational qualification you have achieved?

- |  |   |
|--|---|
| <input type="checkbox"/> Youth training certificate<br><input type="checkbox"/> GCSE's (grades D-G)<br><input type="checkbox"/> Certificate of higher education<br><input type="checkbox"/> Diplomas of higher education/Foundations Degree/Higher National Diploma<br><input type="checkbox"/> Bachelor Degree/Graduate Certificate or Diploma<br><input type="checkbox"/> Masters Degree/Postgraduate Certificate or Diploma<br><input type="checkbox"/> PhD/Doctorate | <input type="checkbox"/> Certificate of Education ( <i>Entry level, no GCSE's</i> )<br><input type="checkbox"/> GCSE's (grades A-C) <input type="checkbox"/> A-levels |
|--|---|

---

5. Did you have a statement of 'special'/educational needs? Yes ☐ No ☐

6. Were you ever excluded from school permanently? Yes ☐ No ☐

(a) If yes, How many times ☐☐

7. Were you ever excluded from school for short periods? Yes ☐ No ☐

(a) If yes, Approximately how many times ☐☐

8. Were you ever excluded from school informally? Yes ☐ No ☐

(a) If yes, how many times ☐☐

9. Who do you usually live with?

Both natural parents ☐ Adoptive Parents ☐

Natural Mother and her partner ☐ Residential home ☐

Natural Father and his partner ☐ Partner ☐

Relative or Family Friends ☐ Partner & children ☐

Formal foster care ☐ Alone ☐

Non-relative ☐

10. In total, how many people live in the house? ☐☐

Over 16 years? ☐☐

Under 16 years? ☐

**Now, can you please tell me something about your daily life...**

**1. Do you go to school or college?**

Yes, full time ☐

Yes, part-time ☐

No, not in education ☐

**2. Do you have a job?**

Yes ☐ (Go to (a)) No ☐ (Go to Q3)

**(a) What type of job is this (can include a Saturday job)?**

**(b) How many hours do you usually work each week?**

**(b) Have you missed work in the last three months  
(SINCE DAY/MONTH)?**

Yes ☐ No ☐

**If YES, (SINCE DAY/MONTH) how many days due to ASD?**

**If YES, (SINCE DAY/MONTH) how many days due to other reasons?**

**(d) Have there been any days in the last 3 months (SINCE DAY/MONTH) when your ASD meant that you felt you couldn't work as well as you usually do?**

Yes ☐ No ☐

**If YES, How many days?**

**3. IF NOT WORKING OR IN EDUCATION, Are you?**

Unemployed ☐

Long-term sick ☐

Volunteer worker ☐

A housewife/husband ☐

Other (describe) \_\_\_\_\_ ☐

**(a) In the last 3 months (SINCE DAY/MONTH), have there been any days when your ASD meant that you felt you couldn't take part in your usual activities?**

Yes ☐ No ☐

If YES, How many days?

**(b) In the last 3 months (SINCE DAY/MONTH), have there been any days when your ASD meant you couldn't do things as well as you usually do?**

Yes ☐ No ☐

If YES, How many days?



<b>Information on service use in last 3 months</b>
--

**1. Have you stayed in hospital for Autism or any mental health problem in the last 3 months (SINCE DAY/MONTH)?**

☐ Yes (1)      ☐ No (0)

If YES,

Admission	Reason for stay	No of inpatient days in the last 3 months
1		
2		
3		

**2. Have you stayed in hospital for other reasons, other than Autism or any mental health problems, in the last 3 months (SINCE DAY/MONTH)?**

☐ Yes (1)      ☐ No (0)

If YES,

Admission	Reason for stay	No of inpatient days in the last 3 months
1		
2		
3		

**3. Have you seen any of the following services in the last 3 months (SINCE DAY/MONTH)? If you're not sure, I'd rather you told me that you're not sure rather than guessed.**

Hospital services	YES	If YES, how many times?	NO
Adult (ASD) outpatient clinic	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Adult outpatient clinic	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
A & E or Minor Injuries Unit	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)

#### 4. And what about the following services?

	YES	If YES, how many times?	NO
Have you seen the GP for Autism in the last 3 months?	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Have you seen the GP for other reasons than for Autism in the last 3 months?	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Have you seen the Practice Nurse for Autism in the last 3 months?	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Have you seen the Practice Nurse for other reasons than for Autism in the last 3 months?	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Have you had any repeat prescriptions in the last 3 months?	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)

#### 5. And have you seen any of the following professionals in the last 3 months (SINCE DAY/MONTH)?

<b>Community Services</b>	YES	If YES, how many times?	NO
Psychiatrist	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Psychiatric Nurse/Nurse Specialist	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Psychologist	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Family Therapist	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Social Worker	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
OT (Occupational Therapist)	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)

**6. And finally, have you seen any of the following professionals in the last 3 months?**

<b>General Community Services</b>	<b>YES</b>	<b>If YES, how many times?</b>	<b>NO</b>
Specialist Doctor (for physical problems)	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Counsellor	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Alternative Therapist (reiki etc): (insert)_____	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Key Worker	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Solicitor or Lawyer	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Self-help/support group	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Home help/home care worker	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Family Support Worker	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Websites/Helplines	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)
Life coach	<input type="checkbox"/> (1)		<input type="checkbox"/> (0)

**7. Have you used any services not listed here? (e.g. family centre)? Please tell us what these services were and how often you used them**

☐ Yes (1) ☐ No (0)

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**8. What about things you pay for? (e.g. special nutritional supplements or over the counter medications)? How often/how much do you pay out of your own pocket?**

☐ Yes (1) ☐ No (0)

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# Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities (CANDID)

## 1. Accommodation

<b>DOES THE PERSON LACK A CURRENT APPROPRIATE PLACE TO LIVE?</b>		<input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/>
What kind of place do you live in? Do you have any problems with your house, flat or room?		
0 = NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN	e.g. The person has an adequate home (even if currently in hospital ).  The person is living in sheltered or residenti accommodations  e.g. The person is homeless, or home lacks bas facilities such as water and electricity.	
IF RATED 0 OR 9 GO TO QUESTION 2		
<b>HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH THEIR ACCOMMODATION?</b>		<input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/>
0= NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH HELP  9 = NOT KNOWN	e.g. Occasionally supplied with items of furniture. e.g. Substantial help with improving accommodation, such as redecoration of flat. e.g. Living with relative because own accommodation is unsatisfactory.	
<b>a)HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR ACCOMMODATION?</b>		<input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/>
<b>b)HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR ACCOMMODATION?</b>		<input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/>
0=NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH 9 = NOT KNOWN	e.g. Minor decoration, was given address of housing ag e.g. Major improvements, referral to housing agency. Being rehoused, living in group home or host	<input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 40px; border: 1px solid black;" type="text"/>

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH THEIR ACCOMMODATION?

(0 = NO 1 = YES 9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING WITH THEIR ACCOMMODATION?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

## 2. Food

**DOES THE PERSON HAVE DIFFICULTY IN GETTING ENOUGH FOOD?**

Do you get enough to eat?

Do you make your own meals? Do you do your own shopping?

0 = NO NEED	e.g.	Able to buy and prepare meals.
1 = MET NEED		Unable to prepare food and has meals provided.
2 = UNMET NEED	e.g.	
9 = NOT KNOWN		Very restricted diet, inappropriate food.

IF RATED 0 OR 9 GO TO QUESTION 3

**HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH GETTING ENOUGH TO EAT?**

0 = NONE		Meals provided weekly or less often.
1 = LOW HELP	e.g.	Weekly help with shopping or meals provided more than weekly but less than daily.
2 = MODERATE HELP	e.g.	
3 = HIGH HELP	e.g.	
9 = NOT KNOWN		Meals provided daily.

**A) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT?**

**B) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT?**

0 = NONE		
1 = LOW HELP	e.g.	1-4 meals a week provided, or assisted for one meal a day
2 = MODERATE HELP	e.g.	More than 4 meals a week provided, or for all meals assisted
3 = HIGH HELP	e.g.	All meals provided.

9 = NOT KNOWN

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a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH GETTING ENOUGH TO EAT?

(0 = NO 1 = YES 9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING IN GETTING ENOUGH TO EAT?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

CAN0213	CAN0214	CAN0215
CAN0216	CAN0217	

### 3. Looking after the home

**DOES THE PERSON HAVE DIFFICULTY LOOKING AFTER THE HOME?**

Are you able to look after your home?

Does anyone help you with keeping your home/flat/room tidy?

0 = NO NEED	Home may be untidy but the person keeps it basically clean.
1 = MET NEED	
2 = UNMET NEED	Unable to look after home and has regular domestic help
9 = NOT KNOWN	e.g. Home is dirty and a potential health hazard.

IF RATED 0 OR 9 GO TO QUESTION 4

**HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH LOOKING AFTER THE HOME?**

0 = NONE	e.g.	
1 = LOW HELP	e.g.	Prompts or helps tidy up or clean occasionally.
2 = MODERATE HELP	e.g.	Prompts or helps clean at least once a week.
3 = HIGH HELP		Supervises the person more than once a week, washes all clothes and cleans the home.
9 = NOT KNOWN		

CAN0301	CAN0302	CAN0303

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a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME?

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b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME?

0= NONE e.g. Prompting by staff  
 1= LOW HELP  
 2= MODERATE HELP e.g. Some assistance with household tasks  
 3= HIGH HELP  
 9 =NOT KNOWN e.g. Majority of household tasks done by staff

CAN0313	CAN0314	CAN0315
CAN0316	CAN0317	

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH LOOKING AFTER THE HOME?

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(0=NO 1=YES 9= NOT KNOWING)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING IN LOOKING AFTER THE HOME  
 (0= NOT SATISFIED 1= SATISFIED 9= NOT KNOWN)

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#### 4. Self care

##### DOES THE PERSON HAVE DIFFICULTY WITH SELF CARE?

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Do you have problems keeping yourself clean and tidy? Do you ever need reminding or help? Who by?

0 = NO NEED e.g. Appearance may be unusual, eccentric or  
 1= MET NEED e.g. untidy, but basically clean,  
 2= UNMET NEED e.g.  
 9 = NOT KNOWN Needs and gets help with self care.  
 Poor personal hygiene, person smells.

IF RATED 0 OR 9 GO TO QUESTION 5

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH THEIR SELF CARE?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>
0= NONE 1=LOW HELP 2= MODERATE HELP 3= HIGH HELP . 9 = NOT KNOWN	e.g. Occasionally prompt to change their clothes. e.g. Run the bath/shower and insist on its use, daily prompting. e.g. Provide daily assistance with several aspects of care.	
a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR SELF CARE?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>
b) HELP DOES PERSON NEED FROM LOCAL SERVICES WITH THEIR SELF CARE?		
0= NONE 1=LOW HELP 2= MODERATE HELP 3= HIGH HELP 9 = NOT KNOWN	e.g. Occasional prompting. e.g. Supervise weekly washing. e.g. Supervise several aspects of self care, self care skills programme.	<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>
a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH SELF CARE?  (0 = NO     1 = YES     9 = NOT KNOWN)		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>
b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF CAN0416 CAN0417 HELP THE PERSON IS RECEIVING WITH SELF CARE?  (0 NOT SATISFIED     1 = SATISFIED 9=NOT KNOWN)		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>



## 5. Daytime activities

<b>DOES THE PERSON HAVE DIFFICULTY WITH REGULAR, APPROPRIATE DAYTIME ACTIVITIES?</b>		<div style="display: flex; justify-content: space-around;"> <div style="text-align: center;">CAN0501 <input style="width: 40px; height: 30px;" type="text"/></div> <div style="text-align: center;">CAN0502 <input style="width: 40px; height: 30px;" type="text"/></div> <div style="text-align: center;">CAN0503 <input style="width: 40px; height: 30px;" type="text"/></div> </div>		
How do you spend your day? Do you have enough to do during the day?				
<table style="width: 100%; border: none;"> <tr> <td style="width: 40%; border: 1px solid black; padding: 5px;">           0= NO NEED            1= MET NEED            2= UNMET NEED            9 = NOT KNOWN         </td> <td style="border: none; padding: 5px;">           e.g. In full time employment, or adequately occupied with household / social activities.            e.g. Unable to occupy self, so attending day centre.            e.g. No employment of any kind and not adequately occupied with household I social activities.         </td> </tr> </table>			0= NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN	e.g. In full time employment, or adequately occupied with household / social activities. e.g. Unable to occupy self, so attending day centre. e.g. No employment of any kind and not adequately occupied with household I social activities.
0= NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN	e.g. In full time employment, or adequately occupied with household / social activities. e.g. Unable to occupy self, so attending day centre. e.g. No employment of any kind and not adequately occupied with household I social activities.			
<b>IF RATED 0 OR 9 GO TO QUESTION 6</b>				
HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES IN FINDING OR KEEPING REGULAR AND APPROPRIATE DAYTIME ACTIVITIES?		<div style="display: flex; justify-content: space-around;"> <div style="text-align: center;">CAN0501 <input style="width: 40px; height: 30px;" type="text"/></div> <div style="text-align: center;">CAN0502 <input style="width: 40px; height: 30px;" type="text"/></div> <div style="text-align: center;">CAN0503 <input style="width: 40px; height: 30px;" type="text"/></div> </div> <div style="display: flex; justify-content: space-around; margin-top: 10px;"> <div style="text-align: center;">CAN0505 <input style="width: 40px; height: 30px;" type="text"/></div> <div style="text-align: center;">CAN0506 <input style="width: 40px; height: 30px;" type="text"/></div> </div>		
0 = NONE 1= LOW HELP      e.g. Occasional advice about daytime activities. 2= MODERATE HELP      e.g. Has arranged daytime activities such as adult education or day centre attendance . 3= HIGH HELP      e.g. Daily help with arranging daytime activities. 9 = NOT KNOWN				
a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN FINDING OR KEEPING REGULAR AND APPROPRIATE DAYTIME ACTIVITIES?		<div style="display: flex; justify-content: space-around;"> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> </div>		
b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN FINDING OR KEEPING REGULAR AND APPROPRIATE DAYTIME ACTIVITIES?		<div style="display: flex; justify-content: space-around;"> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> </div>		
0=NONE 1= LOW HELP      e.g. Employment training / adult education. 2= MODERATE HELP      e.g. Sheltered employment daily. Day centre 2-4 days a week. 3= HIGH HELP      e.g. Attends day hospital or day centre daily. 9 = NOT KNOWN				
a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH DAYTIME ACTIVITIES? (0 = NO      1 = YES      9 = NOT KNOWN)		<div style="display: flex; justify-content: space-around;"> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> </div>		
b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING WITH DAYTIME ACTIVITIES? (0 = NOT SATISFIED      1 = SATISFIED      9= NOT KNOWN)		<div style="display: flex; justify-content: space-around;"> <input style="width: 40px; height: 30px;" type="text"/> <input style="width: 40px; height: 30px;" type="text"/> </div>		

## 6. General physical health

<p><b>DOES THE PERSON HAVE ANY PHYSICAL ILLNESS OR ANY DRUG SIDE EFFECTS? (Excl specific problems rated under domains 7, 8 &amp; 9)</b></p> <div style="text-align: right;"> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> </div> <p>Do you have any problems with your physical health? (e.g. chest, stomach etc) Are you getting any treatment for physical problems from your doctor?</p> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%;">0= NO NEED</td> <td>e.g. Physically well, within the constraints of any longstanding physical impairment.</td> </tr> <tr> <td>1= MET NEED</td> <td>e.g. Physical ailment, such as high blood pressure, receiving appropriate treatment.</td> </tr> <tr> <td>2= UNMET NEED</td> <td></td> </tr> <tr> <td>9 = NOT KNOWN</td> <td>e.g. Untreated physical ailment, including side-effects.</td> </tr> </table> </div> <p style="margin-top: 10px;">IF RATED 0 OR 9 GO TO QUESTION 7</p>		0= NO NEED	e.g. Physically well, within the constraints of any longstanding physical impairment.	1= MET NEED	e.g. Physical ailment, such as high blood pressure, receiving appropriate treatment.	2= UNMET NEED		9 = NOT KNOWN	e.g. Untreated physical ailment, including side-effects.		
0= NO NEED	e.g. Physically well, within the constraints of any longstanding physical impairment.										
1= MET NEED	e.g. Physical ailment, such as high blood pressure, receiving appropriate treatment.										
2= UNMET NEED											
9 = NOT KNOWN	e.g. Untreated physical ailment, including side-effects.										
<div style="text-align: right; font-size: small; margin-bottom: 5px;"> CAN0604      CANC605    CANC60 </div> <p><b>HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES FOR PHYSICAL HEALTH PROBLEMS?</b></p> <div style="text-align: right;"> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> </div> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%;">0= NONE</td> <td>e.g. Prompting to go to doctor.</td> </tr> <tr> <td>1= LOW HELP</td> <td>e.g. Accompanied to doctor.</td> </tr> <tr> <td>2= MODERATE HELP</td> <td>e.g. Daily help with physical health problems.</td> </tr> <tr> <td>3= HIGH HELP</td> <td></td> </tr> <tr> <td>9 = NOT KNOWN</td> <td></td> </tr> </table> </div>		0= NONE	e.g. Prompting to go to doctor.	1= LOW HELP	e.g. Accompanied to doctor.	2= MODERATE HELP	e.g. Daily help with physical health problems.	3= HIGH HELP		9 = NOT KNOWN	
0= NONE	e.g. Prompting to go to doctor.										
1= LOW HELP	e.g. Accompanied to doctor.										
2= MODERATE HELP	e.g. Daily help with physical health problems.										
3= HIGH HELP											
9 = NOT KNOWN											
<p><b>HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR PHYSICAL</b></p> <div style="text-align: right;"> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> </div> <p><b>b)HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR PHYSICAL HEALTH PROBLEMS?</b></p> <div style="text-align: right;"> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> </div>											
0=NONE 1= LOW HELP 2= MODERATE HELP 3= HIGH HELP 9 = NOT KNOWN	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%;">e.g. Given dietary or other health advice.</td> </tr> <tr> <td>e.g. Prescribed medication. Regularly seen by GP / nurse.</td> </tr> <tr> <td>e.g. Frequent hospital appointments.</td> </tr> </table>	e.g. Given dietary or other health advice.	e.g. Prescribed medication. Regularly seen by GP / nurse.	e.g. Frequent hospital appointments.							
e.g. Given dietary or other health advice.											
e.g. Prescribed medication. Regularly seen by GP / nurse.											
e.g. Frequent hospital appointments.											

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR PHYSICAL PROBLEMS?

(0 = NO    1 = YES    9 = NOT KNOWN)

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b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR PHYSICAL PROBLEMS?

(0 = NOT SATISFIED    1 = SATISFIED    NOT KNOWN)

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## 7. Eyesight/hearing

### DOES THE PERSON HAVE ANY PROBLEMS WITH SEEING OR HEARING?

Do you have difficulty in hearing what someone is saying?

Can you see well? (e.g. newspaper, television etc)

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0= NO NEED

e.g. Can see and hear well without aids.

1= MET NEED

e.g. Hearing aid/spectacles required.

2= UNMET NEED

e.g. Very poor eyesight/hearing.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 8

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH THEIR EYESIGHT/HEARING PROBLEMS?

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0 = NONE

e.g. Prompting to seek help or advice.

1= LOW HELP

e.g. Accompanies to appointments, helps with getting aids.

2= MODERATE HELP

e.g. Accompanies almost everywhere outside the house.

3= HIGH HELP

9 = NOT KNOWN

a)HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR EYESIGHT/HEARING PROBLEMS?

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b)HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR EYESIGHT/HEARING PROBLEMS?

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0=NONE

e.g. Advice and minimal support.

1= LOW HELP

e.g. Aids provided. Medical investigations. Some assistance with tasks.

2= MODERATE HELP

3= HIGH HELP

e.g. Assistance several days a week. Frequent hospital appointments.

9 = NOT KNOWN

a) DOES THE PERSON RECEIVE THE RIGHT TYPE  
OF HELP WITH THEIR EYESIGHT/HEARING PROBLEMS?

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(0 = NO      1 = YES      9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT  
OF HELP THE PERSON IS RECEIVING WITH THEIR EYESIGHT/HEARING PROBLEMS?  
(0 = NOT SATISFIED   1 = SATISFIED   NOT KNOWN)

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## 8. Mobility

### DOES THE PERSON HAVE RESTRICTED MOBILITY?

Do you have difficulty moving about inside or outside the house? Do you  
need any help?

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0= NO NEED  
1= MET NEED  
2= UNMET NEED  
9 = NOT KNOWN

e.g. Able to walk unaided.  
e.g. Mobile with some assistance/aids.  
e.g. Not mobile.

IF RATED 0 OR 9 GO TO QUESTION 9

### HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH THEIR MOBILITY PROBLEMS?

CAN0804	CAN0805	CAN0806

0= NONE  
1=LOW HELP  
2=MODERATE HELP  
3= HIGH HELP  
9 = NOT KNOWN

e.g. Occasional help. Prompts to seek help.  
e.g. Regularly accompanies on visits  
e.g. Weekly help. Some home alterations.  
Help several times a week. Considerable home  
alterations,

### A)HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR MOBILITY PROBLEMS?

### B)HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES?

0=NONE      e.g. Receives advice and aids.  
1= LOW HELP      e.g. Regularly seen by physiotherapist/nurse. Weekly  
assistance. Some home alterations.  
2= MODERATE HELP  
3= HIGH HELP      e.g. Assistance several times a week. Purpose built  
Living environment.  
9= NOT KNOWN

CAN0807	CAN0808	CAN0809
CAN0810	CAN0811	CAN0812

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH THEIR MOBILITY PROBLEMS?

(0 = NO      1 = YES      9 = NOT KNOWN)

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b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING WITH THEIR MOBILITY PROBLEMS?

(0 = NOT SATISFIED      1 = SATISFIED      9 = NOT KNOWN)

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## 9. Seizures

**DOES THE PERSON HAVE ANY KIND OF SEIZURES?**

Do you ever get fits of any kind?

Are you getting any treatment for fits from your doctor?

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0 = NO NEED      e.g. No seizures. No antiepileptic medication.  
 1 = MET NEED      e.g. Well-controlled epilepsy. On regular antiepileptic medication.  
 2=UNMET NEED      e.g. Frequent seizures.  
 9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 10

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES FOR THEIR SEIZURES?

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0 = NONE  
 1 = LOW HELP      e.g. Some supervision of medication.  
 2=MODERATE HELP      e.g. Regular supervision of medication.  
 3 = HIGH HELP      e.g. Constant supervision of medication and help with seizures.  
 9 = NOT KNOWN

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THEIR SEIZURES?

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b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THEIR SEIZURES?

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0=NONE  
 1= LOW HELP      e.g. Seizures monitored by GP only.  
 2= MODERATE HELP      e.g. Seizures occasionally monitored by specialist services. Infrequent nurse visits.  
 3= HIGH HELP      e.g. Frequent outpatient appointments or hospital admissions. Frequent specialist nurse visits.  
 9 = NOT KNOWN

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THEIR SEIZURES?

(0 = NO    1 = YES    9 = NOT KNOWN)

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b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR THEIR SEIZURES?

(0 = NOT SATISFIED    1 = SATISFIED    9 = NOT KNOWN)

--	--

## 10. Major mental health problems

**DOES THE PERSON HAVE ANY SYMPTOMS OF SEVERE MENTAL ILLNESS?**

Do you ever hear voices, or have problems with your thoughts?  
Are you on any medication or injections? What is it for?

0 = NO NEED	e.g. No positive symptoms, not at risk from
1= MET NEED	e.g. symptoms and not on medication.
2= UNMET NEED	Symptoms helped by medication or other help.
9 = NOT KNOWN	Currently has symptoms or at risk.

IF RATED 0 OR 9 GO TO QUESTION 11

CAN1001	CAN1002	CAN1003

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES FOR THESE PROBLEMS?

0 = NONE	e.g. Some sympathy and support. Carers involved in helping with coping strategies or medication compliance. e.g. Constant supervision of medication, and help with coping strategies.
1= LOW HELP	
2= MODERATE HELP	
3= HIGH HELP	
9 = NOT KNOWN	

--	--	--

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THESE MENTAL HEALTH PROBLEMS?

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THESE MENTAL HEALTH PROBLEMS?

CAN1007	CAN1008	CAN1009

--	--	--

<p>0= NONE</p> <p>1= LOW HELP                      e.g. Medication reviewed three monthly or less, support group.</p> <p>2= MODERATE HELP    e.g. Medication reviewed more than three monthly. Structured psychological therapy.</p> <p>3= HIGH HELP                      e.g. Medication and 24 hour hospital care or crisis care at home.</p> <p>9 = NOT KNOWN</p>	
<p>a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THESE MENTAL HEALTH PROBLEMS?</p> <p>(0 = NO    1= YES    9 = NOT KNOWN)</p>	<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> </div>
<p>b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR THESE PROBLEMS?</p> <p>(0 = NOT SATISFIED    1 = SATISFIED    9=NOT KNOWN)</p>	<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> </div>

### 11. Other mental health problems

<p><b>DOES THE PERSON SUFFER FROM CURRENT PSYCHOLOGICAL DISTRESS, ANXIETY OR DEPRESSION?</b></p> <p>_____</p> <p>Have you recently felt very sad or low?</p> <p>Have you felt overly anxious or frightened?</p> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>0 = NO NEED                      e.g.    Occasional or mild distress.</p> <p>1 = MET NEED                      Needs and gets ongoing support.</p> <p>2 = UNMET NEED                      Distress affects life significantly, such as preventing person going out.</p> <p>9 = NOT KNOWN</p> </div> <p style="margin-top: 10px;">IF RATED 0 OR 9 GO TO QUESTION 12</p>	<div style="text-align: center; margin-bottom: 5px;"> <span style="font-size: small;">CAN1001</span>    <span style="font-size: small;">CAN1002</span>    <span style="font-size: small;">CAN1003</span> </div> <div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> </div>
<p><b>HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES FOR THIS DISTRESS?</b></p> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>0= NONE</p> <p>1= LOW HELP                      Some sympathy or support.</p> <p>2= MODERATE HELP                      Has opportunity at least weekly to talk about distress to friend or relative.</p> <p>3=HIGH HELP                      Constant support and supervision.</p> <p>9 = NOT KNOWN</p> </div>	<div style="text-align: center; margin-bottom: 5px;"> <span style="font-size: small;">CAN1104</span>    <span style="font-size: small;">CAN1 105</span>    <span style="font-size: small;">CANI 106</span> </div> <div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px;"></div> </div>

<p>a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THIS DISTRESS?</p>	<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> </div> <div style="display: flex; justify-content: space-around; font-size: 8px;"> <span>CAN1110</span> <span>CAN1111</span> <span>CAN1112</span> </div>		
<p>b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THIS DISTRESS?</p>	<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> </div>		
<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%; border-right: 1px solid black; padding-right: 10px;"> <p>0= NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH HELP 9 = NOT KNOWN</p> </td> <td style="padding-left: 10px;"> <p>Assessment of mental state or occasional support. Specific psychological or social treatment for anxiety. Counselling by staff at least once a week. 24 hour hospital care or crisis care.</p> </td> </tr> </table>		<p>0= NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH HELP 9 = NOT KNOWN</p>	<p>Assessment of mental state or occasional support. Specific psychological or social treatment for anxiety. Counselling by staff at least once a week. 24 hour hospital care or crisis care.</p>
<p>0= NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH HELP 9 = NOT KNOWN</p>	<p>Assessment of mental state or occasional support. Specific psychological or social treatment for anxiety. Counselling by staff at least once a week. 24 hour hospital care or crisis care.</p>		
<p>a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THESE MENTAL HEALTH PROBLEMS?</p> <p>(0 = NO      1 = YES   9 = NOT KNOWN)</p> <div style="display: flex; justify-content: flex-end; align-items: center;"> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> </div> <p>c) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR THESE PROBLEMS?</p> <div style="display: flex; justify-content: flex-end; align-items: center;"> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> </div> <p>(0 = NOT SATISFIED      1 = SATISFIED    9= NOT KNOWN)</p>			

## 12. Information (on condition & treatment)

<p><b>HAS THE PERSON HAD CLEAR VERBAL OR WRITTEN INFORMATION ABOUT THEIR CONDITION AND TREATMENT?</b></p> <p>Has anybody explained to you why you need to see the doctor and have tablets or other treatment? Who did? Did you understand this?</p>	<div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 2px;"></div> </div> <div style="display: flex; justify-content: space-around; font-size: 8px;"> <span>CAN1190</span> <span>CAN1191</span> <span>CAN1203</span> </div>		
<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 30%; border-right: 1px solid black; padding-right: 10px;"> <p>0 = NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN</p> </td> <td style="padding-left: 10px;"> <p>e.g. Has received and understood adequate information. e.g. Has not received or understood all information. Has received no information.</p> </td> </tr> </table>		<p>0 = NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN</p>	<p>e.g. Has received and understood adequate information. e.g. Has not received or understood all information. Has received no information.</p>
<p>0 = NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN</p>	<p>e.g. Has received and understood adequate information. e.g. Has not received or understood all information. Has received no information.</p>		
<p><b>IF RATED 0 OR 9 GO TO QUESTION 13</b></p>			



<p>HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES IN OBTAINING SUCH INFORMATION?</p> <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>0 = NONE</p> <p>1= LOW HELP                    e.g. Has had some advice from friends or relatives.</p> <p>2= MODERATE HELP        e.g. Given leaflets/fact-sheets or put in touch with self help groups by friends or relatives.</p> <p>3=HIGH HELP                e.g. Regular liaison with doctors or groups such as MENCAP by friends or relatives.</p> <p>9 NOT KNOWN</p> </div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<div style="border: 1px solid black; padding: 5px;"> <p>0=NONE</p> <p>1= LOW HELP                    e.g. Brief verbal or written information on illness/problem/ treatment.</p> <p>2= MODERATE HELP        e.g. Given details of self-help groups. Long verbal information sessions on drugs and alternative treatments .</p> <p>3= HIGH HELP                e.g. Has been given detailed written information or has had specific personal education.</p> <p>9 = NOT KNOWN</p> </div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 5px;"></div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING INFORMATION?</p> <p>(0 = NO 1 = YES        9 = NOT KNOWN)</p>	
<p>b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING IN OBTAINING INFORMATION?</p> <p>(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)</p>	

### 13. Exploitation risk

#### IS THE PERSON AT RISK OF BEING EXPLOITED OR ABUSED?

Is anyone trying to take advantage of you in any way? (e.g. take money off you or make you do sexual or other things you don't want to do). Can you stand up for yourself and protect yourself or do you need help with this? ..

--	--	--

0= NO NEED  
1= MET NEED  
2= UNMET NEED  
9 .NOT KNOWN

e.g. Not vulnerable to exploitation/abuse, Needs and gets ongoing support and protection.  
Subject of regular verbal abuse, any financial misappropriation, physical or sexual abuse.

IF RATED 0 OR 9 GO TO QUESTION 14

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES TO REDUCE THE RISK OF EXPLOITATION/ABUSE?

--	--

0= NONE

1 = LOW HELP e.g. Able to contact friends or relatives if feeling unsafe.  
2= MODERATE HELP e.g. Friends or relatives are usually in contact and are likely to know if feeling unsafe.

3= HIGH HELP Friends or relatives in regular contact and are very likely to know and provide help if feeling unsafe.

9 = NOT KNOWN

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF EXPLOITATION/ABUSE?

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b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF EXPLOITATION/ABUSE?

--	--	--

0= NONE

1= LOW HELP e.g. Someone to contact when feeling vulnerable.

2= MODERATE HELP e.g. Regular monitoring and support.

3= HIGH HELP e.g. Constant supervision, legal involvement via services.

9 = NOT KNOWN

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE THE RISK OF EXPLOITATION/ABUSE?

(0 = NO 1 = YES 9 = NOT KNOWN)

--	--	--

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE THE RISK OF EXPLOITATION/ ABUSE?

(0 = NOT SATISFIED 1 = SATISFIED 9=NOT KNOWN)

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## 14. Safety of self

### IS THE PERSON A DANGER TO THEMSELVES?

Do you ever have thoughts of harming yourself? Do you ever actually harm yourself? Do you put yourself in danger in any other way?

CAN140	CAN140	CAN140
<input type="text"/>	<input type="text"/>	<input type="text"/>

0= NO NEED  
1= MET NEED  
2= UNMET NEED

No suicidal thoughts. No self injury.  
Suicide/self injury risk monitored by staff, receiving counselling.  
Has expressed suicidal ideas during last month or has exposed themselves to serious danger.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 15

### HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES TO REDUCE THE RISK THAT THEY MIGHT HARM THEMSELF?

CAN14C4	CAN14C5	CAN14C6
<input type="text"/>	<input type="text"/>	<input type="text"/>

0 = NONE  
1 = LOW HELP  
2=MODERATE HELP  
3=HIGH HELP  
9 = NOT KNOWN

e.g. Able to contact friends or relatives if feeling unsafe.  
Friends or relatives are usually in contact and are likely to know if user is feeling unsafe.  
Friends or relatives in regular contact and are very likely to know and provide help if user is feeling unsafe.

### a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK THAT THEY MIGHT HARM THEMSELF?

### b)HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK THAT THEY MIGHT HARM THEMSELVES?

CAN1407	CAN1408	CAN1409
<input type="text"/>	<input type="text"/>	<input type="text"/>

0=NONE  
1= LOW HELP e.g. Someone to contact when feeling unsafe.  
2= MODERATE HELP e.g. Staff check at least once a week, regular supportive counselling.  
3= HIGH HELP e.g. Daily supervision, inpatient care.  
9 = NOT KNOWN

### a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE THE RISK THAT THEY MIGHT HARM THEMSELVES?

(0 = NO 1 = YES 9 = NOT KNOWN)

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

### b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING TO REDUCE THE RISK THAT THEYMIGHT HARM THEMSELVES?

<input type="text"/>	<input type="text"/>
----------------------	----------------------

(0 = NOT SATISFIED    1 = SATISFIED    9=NOT KNOWN)

### 15. Safety of others

**IS THE PERSON A CURRENT OR OTENTIAL RISK TO OTHER PEOPLE'S SAFETY?**

--	--	--

Do you think you could be a danger to other people?

Do you ever lose your temper and hit people?

0= NO NEED	e.g. Help with threatening behaviour weekly or less.
1= MET NEED	
2= UNMET NEED	e.g. Help with threatening behaviour more than weekly.
9 = NOT KNOWN	e.g. Almost constant help with persistently threatening behaviour

**HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES TO REDUCE THE RISK THAT THEY MIGHT HARM SOMEONE ELSE?**

--	--	--

0= NONE	Help with threatening behaviour weekly or less.
1= LOW HELP	Help with threatening behaviour more than weekly.
2= MODERATE HELP	
3=HIGH HELP	Almost constant help with persistently threatening behaviour.
9 = NOT KNOWN	

**a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK THAT THEY MIGHT HARM SOMEONE ELSE?**

--	--	--

CAN1512

**b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK THAT THEY MIGHT HARM SOMEONE ELSE?**

--	--	--

0=NONE	
1= LOW HELP	e.g. Check on behaviour weekly or less.
2= MODERATE HELP	e.g. Daily supervision.
3= HIGH HELP	e.g. Constant supervision. Anger management program.
9 = NOT KNOWN	

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP  
TO REDUCE THE RISK THAT THEY MIGHT HARM SOMEONE ELSE?  
(0 = NO    1 = YES    9 = NOT KNOWN)

CAN131	CAN151	CAN151
<input type="text"/>	<input type="text"/>	<input type="text"/>

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE  
PERSON IS RECEIVING TO REDUCE THE RISK THAT THEY  
MIGHT HARM SOMEONE ELSE?

<input type="text"/>	<input type="text"/>
----------------------	----------------------

(0 = NOT SATISFIED    1 = SATISFIED    9=NOT KNOWN)

## 16. Inappropriate behaviour

### IS THE PERSON INTERFERING OR OBJECTIONABLE TO OTHERS?

(Excl. specific problems rated under domains 14, 15 & 20)

Do other people get annoyed, upset or angry because of your behaviour? What happens?

- |               |   |
|---------------|---|
| 0= NO NEED    | e. Such behaviour is not an issue.        |
| 1= MET NEED   | g. Under supervision because of potential |
| 2=UNMETNEED   | e. risk. Regular socially unacceptable    |
| 9 = NOT KNOWN | g. behaviour                              |

IF RATED 0 OR 9 GO TO QUESTION 17

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES TO REDUCE THE RISK OF DISTURBING OTHERS?

- |                  |  |
|------------------|--|
| 0=NONE           | e.g. Some supervision, weekly or less. |
| 1= LOW HELP      | e.g. Supervision several days a week.  |
| 2= MODERATE HELP | e.g. Constant supervision              |
| 3= HIGH HELP     |  |
| 9= NOT KNOWN     |  |

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF DISTURBING OTHERS?

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF DISTURBING OTHERS?

- |                  |  |
|------------------|--|
| 0=NONE           | e.g. Check on behaviour weekly or less.                              |
| 1= LOW HELP      | e.g. Daily supervision. Behaviour management programme               |
| 2= MODERATE HELP | e.g. Constant supervision. Intensive involvement of specialist team. |
| 3= HIGH HELP     |  |
| 9= NOT KNOWN     |  |

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE THE RISK OF DISTURBING OTHERS?

(0 = NO 1 = YES 9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING TO REDUCE THE RISK OF DISTURBING OTHERS?

(0= NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

## 17. Substance misuse (alcohol and drugs)

### DOES THE PERSON HAVE AN ALCOHOL OR DRUG PROBLEM?

Does drinking alcohol cause you any problems? Do you take any drugs that are not prescribed by the doctor? Do you find it difficult to stop?

CANP70	CANP02	CANP03
<input type="text"/>	<input type="text"/>	<input type="text"/>

- |               |      |   |
|---------------|------|---|
| 0= NO NEED    | e.g. | No alcohol or drug problem.                       |
| 1= MET NEED   | e.g. | At risk from substance misuse and receiving help. |
| 2= UNMET NEED |      |   |
| 9 = NOT KNOWN |      | Harmful or uncontrollable use.                    |

IF RATED 0 OR 9 GO TO QUESTION 18

### HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES FOR THEIR SUBSTANCE MISUSE?

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

- |                  |      |   |
|------------------|------|---|
| 0= NONE          | e.g. | Occasional advice or support.                       |
| 1= LOW HELP      | e.g. | Regular advice, put in touch with helping agencies. |
| 2= MODERATE HELP | e.g. | Daily monitoring of use.                            |
| 3= HIGH HELP     |      |   |
| 9 = NOT KNOWN    |      |   |

### a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THEIR SUBSTANCE MISUSE?

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

### b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THEIR SUBSTANCE MISUSE?

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

- |                  |      |  |
|------------------|------|--|
| 0= NONE          | e.g. | Occasional professional advice.                            |
| 1= LOW HELP      | e.g. | Given details of helping agencies.                         |
| 2= MODERATE HELP | e.g. | Attends specialist clinic. Supervised withdrawal programme |
| 3= HIGH HELP     |      |  |
| 9 = NOT KNOWN    |      |  |

### a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THEIR SUBSTANCE MISUSE?

(0 = NO    1 = YES    9 = NOT KNOWN)

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

### b) OVERALL, IS THE RESPONDER SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR THEIR SUBSTANCE MISUSE?

(0= NOT SATISFIED    1 = SATISFIED    9 = NOT KNOWN)

<input type="text"/>	<input type="text"/>
----------------------	----------------------

## 18. Communication

### CAN THE PERSON COMMUNICATE WITH OTHERS?

Can you understand what other people say to you?  
Can they understand you?

0= NO NEED	e.g. Able to understand and make self-understood.
1= MET NEED	e.g. Some difficulty but able to communicate with help
2= UNMET NEED	
9 = NOT KNOWN	Severe problems with understanding or making self-understood

### IF RATED 0 OR 9 GO TO QUESTION 19

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH COMMUNICATION DIFFICULTIES?

0= NONE	e.g. Only minimal facilitation of communication.
1= LOW HELP	e.g. Occasional interpretation.
2= MODERATE HELP	Accompanies person to make communication possible.
3= HIGH HELP	
9 = NOT KNOWN	

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH COMMUNICATION DIFFICULTIES?

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH COMMUNICATION?

0= NONE	e.g. Some advice.
1= LOW HELP	e.g. Communication skills training
2= MODERATE HELP	e.g. Speech therapist involvement.
3= HIGH HELP	
9 = NOT KNOWN	

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR COMMUNICATION DIFFICULTIES?

(0 = NO    1 = YES    9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDER SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING WITH COMMUNICATION DIFFICULTIES?

(0= NOT SATISFIED    1 = SATISFIED    9 = NOT KNOWN)



## 19. Social Relationships

<b>DOES THE PERSON NEED HELP WITH SOCIAL CONTACT?</b> Do you have any sexual difficulties?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
<table style="width: 100%; border: none;"> <tr> <td style="width: 30%; vertical-align: top;">           0= NO NEED            1= MET NEED            2= UNMET NEED            9 = NOT KNOWN         </td> <td style="width: 70%; vertical-align: top;">           e.g. Able to organise enough social contact, has enough friends.            Needs help with social contact and is receiving it. Attends appropriate drop-in or day centre.            Frequently feels lonely or isolated.         </td> </tr> </table>			0= NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN	e.g. Able to organise enough social contact, has enough friends. Needs help with social contact and is receiving it. Attends appropriate drop-in or day centre. Frequently feels lonely or isolated.
0= NO NEED 1= MET NEED 2= UNMET NEED 9 = NOT KNOWN	e.g. Able to organise enough social contact, has enough friends. Needs help with social contact and is receiving it. Attends appropriate drop-in or day centre. Frequently feels lonely or isolated.			
IF RATED 0 OR 9 GO TO QUESTION 20				
<b>MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH SOCIAL CONTACT?</b>		<div style="display: flex; justify-content: space-around; font-size: 0.8em;"> <span>CAN1904</span> <span>CAN1905</span> <span>CAN1906</span> </div> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
<table style="width: 100%; border: none;"> <tr> <td style="width: 30%; vertical-align: top;">           0= NONE            1= LOW HELP            2= MODERATE HELP            3= HIGH HELP            9 = NOT KNOWN         </td> <td style="width: 70%; vertical-align: top;">           e.g. Social contact less than weekly.            Social contact weekly or more often.            Social contact at least four times a week.         </td> </tr> </table>			0= NONE 1= LOW HELP 2= MODERATE HELP 3= HIGH HELP 9 = NOT KNOWN	e.g. Social contact less than weekly. Social contact weekly or more often. Social contact at least four times a week.
0= NONE 1= LOW HELP 2= MODERATE HELP 3= HIGH HELP 9 = NOT KNOWN	e.g. Social contact less than weekly. Social contact weekly or more often. Social contact at least four times a week.			
a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
0=NONE 1= LOW HELP 2= MODERATE HELP 3=HIGH HELP 9 = NOT KNOWN		<div style="display: flex; justify-content: space-around; font-size: 0.8em;"> <span>CAN1910</span> <span>CAN1911</span> <span>CAN1912</span> </div> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
e.g. Given advice about social clubs. e.g. Day centre or community group up to 3 times a week. e.g. Attends day centre 4 or more times a week.		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN ORGANISING SOCIAL CONTACT?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
(0 = NO    1 = YES    9 = NOT KNOWN)		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN ORGANISING SOCIAL CONTACT?		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		
(0 = NOT SATISFIED    1 = SATISFIED    9=NOT KNOWN)		<input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 40px; height: 30px; border: 1px solid black;" type="text"/>		

## 20. Sexual expression

### DOES THE PERSON HAVE PROBLEMS WITH THEIR SEX LIFE?

Do you have any sexual difficulties?

- |               |      |   |
|---------------|------|---|
| 0= NO NEED    | e.g. | Happy with current sex life.  |
| 1=MET NEED    | e.g. | Benefiting from sex therapy, sex education                                      |
| 2= UNMET NEED | e.g. | programme.  |
| 9 = NOT KNOWN |      | Serious sexual difficulty. Very limited or no sex life despite existing desire. |

--	--	--

IF RATED 0 OR 9 GO TO QUESTION 21

### HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH PROBLEMS IN THEIR SEX LIFE?

- |                  |      |  |
|------------------|------|--|
| 0= NONE          | e.g. |  |
| 1= LOW HELP      |      | Some advice.   |
| 2= MODERATE HELP |      | Several talks, information material, providing contraceptives etc.                                 |
| 3= HIGH HELP     |      | Consistent accessibility to talk about the problem. Facilitates contact with counselling services. |
| 9=NOT KNOWN      |      |  |

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### a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR PROBLEMS IN THEIR SEX LIFE?

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### b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR PROBLEMS IN THEIR SEX LIFE?

--	--	--

- |                  |   |
|------------------|---|
| 0=NONE           |   |
| 1= LOW HELP      | Some information about sexual matters such as contraception, safe sex, drug-induced impotence . |
| 2= MODERATE HELP | e.g. Regular discussions on sex issues. Medical investigations.                                 |
| 3= HIGH HELP     | e.g. Sex therapy. Sex education programme. Other medical treatment.                             |
| 9 = NOT KNOWN    |   |

### a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR PROBLEMS IN THEIR SEX LIFE?

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(0 = NO    1 = YES    9 = NOT KNOWN)

### b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THE PERSON IS RECEIVING FOR PROBLEMS IN THEIR SEX LIFE?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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## 21. Caring for someone else

### DOES THE PERSON HAVE DIFFICULTY LOOKING AFTER ANOTHER PERSON?

Do you have any children (under 18) or a relative that you are looking after? Do you have any difficulty in looking after them?

--	--	--

- |               |   |
|---------------|---|
| 0 = NO NEED   | e.g. Nobody to look after or no problem with looking              |
| 1= MET NEED   | e.g. after them.  |
| 2= UNMET NEED | e.g. Difficulties with caring and receiving help.                 |
| 9 = NOT KNOWN | Serious difficulty looking after children or dependent relatives. |

IF RATED 0 OR 9 GO TO QUESTION 22

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH LOOKING AFTER THEIR CHILDREN OR RELATIVES?

--	--	--

- |                   |   |
|-------------------|---|
| 0= NONE           | e.g. Occasional help less than once a week.                   |
| 1= LOW HELP       | Help most days of the week.                                   |
| 2 = MODERATE HELP |   |
| 3 = HIGH HELP     | e.g. Children/sick relative living with friends or relatives. |
| 9 = NOT KNOWN     |   |

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH LOOKING AFTER THEIR CHILDREN/RELATIVES?

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b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH LOOKING AFTER THEIR CHILDREN/RELATIVES?

--	--	--

- |                  |  |
|------------------|--|
| 0=NONE           |  |
| 1=LOW HELP       | e.g. Attending day nursery/day care, weekly assistance at home.          |
| 2= MODERATE HELP | Nearly daily assistance. Given training in caring skills.                |
| 3=HIGH HELP      | e.g. Children/relatives in residential care or other 24 hr care package. |
| 9 = NOT KNOWN    |  |

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR LOOKING AFTER THEIR CHILDREN/RELATIVES?

(0 = NO 1 = YES 9 = NOT KNOWN)

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b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH LOOKING AFTER THEIR RELATIVES?

(0 = NOT SATISFIED      1 = SATISFIED      9=NOT KNOWN)

## 22. Basic education

### DOES THE PERSON LACK BASIC SKILLS IN NUMERACY & LITERACY?

Do you have difficulty with reading, writing? Can you count your change in a shop?

0=NO NEED	e.g.	Able to read, write and understand English.
1=MET NEED	e.g.	Difficulties with reading and has help.
2 = UNMET NEED	e.g.	Difficulty with basic skills.
9 = NOT KNOWN		

IF RATED 0 OR 9 GO TO QUESTION 23

### HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH NUMERACY AND LITERACY?

0= NONE	e.g.	Occasional help to read or write forms.
1= LOW HELP	e.g.	Has put them in touch with literacy classes.
2= MODERATE HELP		Teaches the person to read.
3= HIGH HELP		
9 = NOT KNOWN		

### a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH NUMERACY AND LITERACY?

### b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH NUMERACY AND LITERACY?

0= NONE		
1= LOW HELP	e.g.	Help filling in forms.
2= MODERATE HELP	e.g.	Given advice about classes.
3= HIGH HELP	e.g.	Attending adult education.
9 NOT KNOWN		

a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH NUMERACY AND LITERACY?

(0 = NO 1 = YES 9 = NOT KNOWN)

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b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH NUMERACY AND LITERACY?

(0 = NOT SATISFIED 1 = SATISFIED 9=NOT KNOWN)

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## 23. Transport

**DOES THE PERSON HAVE ANY PROBLEMS USING PUBLIC TRANSPORT?**

How do you go to different places outside your house? Can you travel by bus, tube or train? Does anyone help you? Do you have a free bus pass?

0= NO NEED  
1=MET NEED  
2= UNMET NEED  
9 = NOT KNOWN

e.g. Able to use public transport, or has access to car.  
Bus pass or other help provided with transport.  
Unable to use public transport. No other transport easily available.

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IF RATED 0 OR 9 GO TO QUESTION 24

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES WITH TRAVELLING?

0= NONE  
1= LOW HELP  
2= MODERATE HELP  
3= HIGH HELP  
9 = NOT KNOWN

e.g. Encouragement to travel.  
Often accompanies on public transport.  
Provides transport to all appointments.

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a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH TRAVELLING?

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH TRAVELLING?

0=NONE  
1= LOW HELP  
2= MODERATE HELP  
3= HIGH HELP  
9 = NOT KNOWN

Provision of bus pass.  
e.g. Taxi card.  
Transport to appointments by ambulance etc.

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a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH TRAVELLING?

(0 = NO      1= YES      9 = NOT KNOWN)

--	--	--

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH TRAVELLING?

(0 = NOT SATISFIED      1 = SATISFIED      9 = NOT KNOWN)

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## 24. Money budgeting

**DOES THE PERSON HAVE PROBLEMS BUDGETING THEIR MONEY?**

How do you find budgeting your money?

Do you manage to pay your bills yourself? Does anyone help you?

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0= NO NEED

1= MET NEED

2= UNMET NEED

9= NOT KNOWN

e.g. Able to buy essential items and pay bills.

Benefits from help with budgeting.

Unable to manage finances.

IF RATED 0 OR 9 GO TO QUESTION 25

HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES IN MANAGING THEIR MONEY?

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0= NONE

1= LOW HELP

2= MODERATE HELP

3= HIGH HELP

9 = NOT KNOWN

Occasional help sorting out household bills.

Calculating weekly budget.

Complete control of finances.

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

--	--	--

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

0=NONE

1= LOW HELP

2=MODERATE HELP

3= HIGH HELP

9 NOT KNOWN

e.g. Occasional help with budgeting.

Supervised in paying rent, given weekly spending money.

Daily handouts of cash.

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a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN MANAGING THEIR MONEY?

(0 = NO      1 = YES      9 = NOT KNOWN)

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN MANAGING THEIR MONEY?

(0 = NOT SATISFIED      1 = SATISFIED      9 = NOT KNOWN)

CAN2416	CAN2417	

## 25. Welfare benefits

**IS THE PERSON DEFINITELY RECEIVING ALL THE BENEFITS THAT THEY ARE ENTITLED TO?**

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Are you sure that you are getting all the benefits you are entitled to?

0= NO NEED	e.g. Receiving full entitlement of benefits.
1= MET NEED	Receives appropriate help in claiming
2= UNMET NEED	benefits.
9= NOT KNOWN	Not sure/not receiving full entitlement of
	benefits.

IF RATED 0 OR 9 CANDID-R IS COMPLETED

**HOW MUCH HELP DOES THE PERSON RECEIVE FROM FRIENDS OR RELATIVES IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?**

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0= NONE	e.g. Occasionally asks whether person is getting any money.
1= LOW HELP	e.g. Has helped fill in forms.
2= MODERATE HELP	e.g. Has made enquiries about full entitlements.
3= HIGH HELP	
9= NOT KNOWN	

a) HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

b) HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

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0=NONE	e.g. Occasional advice about entitlements
1= LOW HELP	e.g. Help with applying for extra entitlements
2= MODERATE HELP	e.g. Comprehensive evaluation of current entitlements
3= HIGH HELP	
9= NOT KNOWN	

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a) DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?

(0 = NO    1 = YES    9 = NOT KNOWN)

--	--	--

b) OVERALL, IS THE RESPONDENT SATISFIED WITH THE AMOUNT OF HELP IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?

(0 = NOT SATISFIED    1 = SATISFIED    9 = NOT KNOWN)

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## Appendix E

### Stage Two: Adult with ASD topic guide

ADULT WITH ASD TOPIC GUIDE
<p><b>Introduction</b></p> <ul style="list-style-type: none"><li>• Introduce self</li><li>• Explain the purpose and nature of the project and their role in the study</li><li>• Obtain written consent for participation and consent for use of Dictaphone</li><li>• Explain confidentiality and anonymity</li></ul>
<p><b>About the Sibling Relationship</b></p> <p>Can you describe for me your relationship with your brother/sister?</p> <p><i>Prompts:</i></p> <ul style="list-style-type: none"><li>• <i>Interactions (social/recreational, frequency)</i></li><li>• <i>Satisfaction with amount of interactions (too much/too little)</i></li><li>• <i>Support (companionship, emotional, financial, caregiving, ADLs, IADLS)</i></li><li>• <i>Living arrangements</i></li><li>• <i>Transportation</i></li><li>• <i>Types of care required e.g. personal hygiene</i></li><li>• <i>Overall a positive relationship</i></li></ul>
<p><b>Relationship changes over time</b></p> <p>How (if at all) has your relationship with your sibling and your parents changed in the last 5 years?</p> <p><i>Prompt:</i></p> <ul style="list-style-type: none"><li>• <i>Less/ More interactions</i></li><li>• <i>Less/More responsibilities, role in caregiving</i></li></ul>
<p><b>Future relationship</b></p> <p>What do you expect your relationship to be like in 5-10 years time?</p>

*Prompt*

- *Less/ More interactions*
- *Less/More responsibilities, role in caregiving*
- *Legal, Financial, guardianship*
- *Living arrangement*

**Parental Wellbeing**

From your perspective can you tell me about your parents' wellbeing?

*Prompts*

- *Health (physical and mental capacities)*
- *Supports and resources*
- *Both parents alive, marital status*

**Future Care Plan**

Do you think you will need support in the future? What are your preferences for future support? Who from?

- *Live alone*
- *Live with your sibling or other people*
- *Continue living where you are*

Does your family have a plan for your future support and wellbeing? An emergency plan?

- *Have your parent's discussed it with you? With your brother/sister?*
- *Or is it just implied?*
- *All in agreement?*
- *Concerns*

**Supportive Needs**

What kind of support would you need? What would help to make it easier for a sibling or other person to support you?

*Prompts:*

- *Formal support e.g. professionals, respite care, day services etc*
- *Help with specific care needs e.g. care of an intimate/personal nature*
- *Informal support e.g. family, friends, other carers*
- *Financial support*
- *Religion*
- *Other*

### **Timing of Planning and Preparation for transition out of parental care**

1. When do you think families with a child with autism should begin planning for the transition out of their parents' care?

*Prompts*

- *By a certain age, disability level, parent's health*
- *Who should bring up the topic (family, professionals)*
- *When should the transition begin*

2. How do you think families with a child with autism should prepare for the transition out of their parents' care?

*Prompts:*

- *Family discussions*
- *Legal arrangements*
- *Investigate Housing options and timing*
- *Financial arrangements*

### **Suggestions**

What advice about future planning would you give parents of children with autism?

*Prompts*

- *What would be helpful to encourage carers to make future plans for their relative with a learning disability?*
- *Information*
- *Respite care*
- *Guidance/Support*

**Is there anything else you would like to tell me?**

**Are there any other comments that you would like to make?**

### **Close**

Thank participants for their time and inform them of what happens to the information.

## Stage Two: Parent topic guide

### PARENT TOPIC GUIDE

#### Introduction

- Introduce self
- Explain the purpose and nature of the project and their role in the study
- Obtain written consent for participation and consent for use of Dictaphone
- Explain confidentiality and anonymity

#### About the Adult with Autism

1. Can you tell me a bit about your son/daughter with ASD? What support does he/she need?

*Prompt:*

- *Severity of LD e.g. mild, moderate, severe, or profound*
- *Challenging behaviour*
- *Physical and mental health*
- *Level of dependence*
- *Routines and patterns*
- *Types of care required e.g. personal hygiene*
- 

#### Carer Health Status

2. Can you tell me about your health status?

*Prompt:*

- *Physical health*
- *Mental health*
- *Changed over the years as a result of caring e.g. transitions*

#### Health Status of Significant Other in the household

3. Can you tell me about the health status of your partner?

*Prompt:*

- *Physical health*
- *Mental health*
- *Changed over the years as a result of caring e.g. transitions*

#### Support services

4. What types of supports, if any, do you receive at present in helping you care for your adult child with autism?

*Prompts:*

- *Statutory services e.g. day centre, respite, domiciliary care*
- *Voluntary services e.g. clubs and activities*
- *Informal support from family and friends*
- *Financial support*
- *Other support*
- *Changes in support over the years?*

5. Are you satisfied with the amounts and types of support you receive at present in caring for your adult child with autism?

*Prompts:*

- *Formal support*
- *Informal support*
- *Suggestions for improvement*

6. What in particular has enabled you to continue caring for your son/daughter with autism in the home?

*Prompts:*

- *Formal support e.g. professionals, respite care, day services etc.*
- *Informal support e.g. family, friends, other carers*
- *Financial support*
- *Religion*
- *Help with specific care needs e.g. care of an intimate/personal nature*
- *Other*

### **Changing caregiving role**

7. How, if at all, has your role as a carer changed over the years?

*Prompts:*

- *Getting easier*
- *More difficult*
- *Reliance on Person with autism to care for them*

8. If your role has changed, why? What has contributed to this change?

*Prompts:*

- *Own physical health needs, limitations*
- *Changing needs of Person with autism*
- *Compound caring needs (added care for spouse, parent)*

9. How if at all, do you think caring for your son or daughter with autism impacted on you in terms of:

*Prompts:*

- *Your health e.g. physical and mental*
- *Employment opportunities e.g. financial*
- *Socialisation e.g. friends, outings*

### **Future planning**

10. Have you made any plans for the future for your adult child with autism? What are your preferences for his/her long-term care? Do you have an emergency plan established?

*Prompts:*

- *To remain within their family home with formal support*
- *To live with other family members (who and where)*
- *To live within a residential facility/nursing home*
- *To be admitted to a LD hospital*

11. What do you perceive to be (if anything) the barriers to carers making future plans for their relative with autism?

*Prompts:*

- *Lack of information*
- *Dissatisfaction with potential placements*
- *Concerns about the future for the person with autism*
- *Carers reliance on person with autism to care for them*

12. What would be helpful for carers to make future plans for their relative with autism?

*Prompts:*

- *Information*
- *Guidance and support*
- *Legal advice*

**Is there anything else you would like to tell me?**

**Are there any other comments that you would like to make?**

### **Close**

Thank participants for their time and inform them of what happens to the information

## Stage Two: Sibling topic guide

### SIBLING TOPIC GUIDE

#### Introduction

- Introduce self
- Explain the purpose and nature of the project and their role in the study
- Obtain written consent for participation and consent for use of Dictaphone
- Explain confidentiality and anonymity

#### About the Sibling Relationship

Can you describe for me your relationship with your brother/sister with autism?

*Prompts:*

- *Interactions (social/recreational, frequency)*
- *Satisfaction with amount of interactions (too much/too little)*
- *Support (companionship, emotional, financial, caregiving, ADLs, IADLS)*
- *Living arrangements*
- *Transportation*
- *Types of care required e.g. personal hygiene*
- *Overall a positive relationship*

#### Relationship changes over time

How (if at all) has your relationship with your sibling changed in the last 5 years?

*Prompt:*

- *Less/ More interactions*
- *Less/More responsibilities, role in caregiving*

#### Future relationship

What do you expect your relationship to be like in 5-10 years time?

*Prompt*

- *Less/ More interactions*
- *Less/More responsibilities, role in caregiving*
- *Legal, Financial, guardianship*
- *Living arrangement*

### **Parental Wellbeing**

From your perspective can you tell me about your parents' wellbeing?

*Prompts*

- *Health (physical and mental capacities)*
- *Supports and resources*
- *Both parents alive, marital status*

### **Future Care Plan**

Do you think your brother/sister will need support in the future? With what will he/she need support? What are your preferences for his or her future support? Who from?

- Live alone
- Live with you or other people
- Continue living where he/she is

Does your family have a plan for the future care and wellbeing of your sibling with ASD?

An emergency plan?

- *Have your parent's discussed it with you? With your brother/sister?*
- *Or is it just implied?*
- *All in agreement?*
- *Concerns*

### **Timing of Planning and Preparation for transition out of parental care**

3. When do you think families with a child with autism should begin planning for the transition out of their parents' care?

*Prompts*

- *By a certain age, disability level, parent's health*
- *Who should bring up the topic (family, professionals)*
- *When should the transition begin*

4. How do you think families with a child with autism should prepare for the transition out of their parents' care?

*Prompts:*

- *Family discussions*
- *Legal arrangements*



- *Investigate Housing options and timing*
- *Financial arrangements*

### **Supportive Needs**

What would help to make it easier for you to support your brother/sister with autism?

*Prompts:*

- *Formal support e.g. professionals, respite care, day services etc*
- *Help with specific care needs e.g. care of an intimate/personal nature*
- *Informal support e.g. family, friends, other carers*
- *Financial support*
- *Religion*
- *Other*

### **Suggestions**

What advice about future planning would you give parents of children with autism?

*Prompts*

- *What would be helpful to encourage carers to make future plans for their relative with a learning disability?*
- *Information*
- *Respite care*
- *Guidance/Support*

**Is there anything else you would like to tell me?**

**Are there any other comments that you would like to make?**

### **Close**

Thank participants for their time and inform them of what happens to the information.

## Stage Two: Partner topic guide

PARTNER TOPIC GUIDE	
<b>Introduction</b>	<ul style="list-style-type: none"><li>• Introduce self</li><li>• Explain the purpose and nature of the project and their role in the study</li><li>• Obtain written consent for participation and consent for use of Dictaphone</li><li>• Explain confidentiality and anonymity</li></ul>
<b>About the Adult with Autism</b>	<p>13. Can you tell me a bit about your relationship with your partner? (with an adult with autism?)</p> <p><i>Prompt:</i></p> <ul style="list-style-type: none"><li>• <i>Severity of LD e.g. mild, moderate, severe, or profound</i></li><li>• <i>Challenging behaviour</i></li><li>• <i>Physical and mental health</i></li><li>• <i>Level of dependence</i></li><li>• <i>Routines and patterns</i></li><li>• <i>Types of care required e.g. personal hygiene</i></li></ul>
<b>Partner Health Status</b>	<p>14. Can you tell me about your health status?</p> <p><i>Prompt:</i></p> <ul style="list-style-type: none"><li>• <i>Physical health</i></li><li>• <i>Mental health</i></li><li>• <i>Changed over the years as a result of caring</i></li></ul>
<b>Support services</b>	<p>15. What types of supports, if any, do you receive at present to help you?</p> <p><i>Prompts:</i></p> <ul style="list-style-type: none"><li>• <i>Statutory services e.g. day centre, respite, domiciliary care</i></li><li>• <i>Voluntary services e.g. clubs and activities</i></li><li>• <i>Informal support from family and friends</i></li><li>• <i>Financial support</i></li><li>• <i>Other support</i></li><li>• <i>Changes in support over the years?</i></li></ul>

16. Are you satisfied with the amounts and types of support you receive at present?

*Prompts:*

- *Formal support*
- *Informal support*
- *Suggestions for improvement*

17. What in particular has helped you to support your partner? (with autism?)

*Prompts:*

- *Formal support e.g. professionals, respite care, day services etc.*
- *Informal support e.g. family, friends, other carers*
- *Financial support*
- *Religion*
- *Help with specific care needs e.g. care of an intimate/personal nature*
- *Other*

### **Changing caregiving role**

18. Has your support role changed over the years?

*Prompts:*

- *Getting easier*
- *More difficult*
- *Reliance on Person with autism to care for them*

19. If your role has changed, why? What has contributed to this change?

*Prompts:*

- *Own physical health needs, limitations*
- *Changing needs of Person with autism*
- *Compound caring needs (added care for spouse, parent)*

20. Do you think caring for your partner with autism has impacted you in terms of:

*Prompts:*

- *Your health e.g. physical and mental*
- *Employment opportunities e.g. financial*
- *Socialisation e.g. friends, outings*

### **Future planning**

21. Do you think your partner would need support in the future if they did not have you? Have you made any plans for the future? (for your partner with autism?) What are your preferences for his/her long-term care? Do you have an emergency plan established?

*Prompts:*

- *To remain within the family home with formal or informal support*

- *To live with other family members (who and where)*
- *To live within a residential facility/nursing home*

22. What do you think would be helpful to make future care plans?

*Prompts:*

- *Information*
- *Guidance and support*
- *Legal advice*

**Is there anything else you would like to tell me?**

**Are there any other comments that you would like to make?**

**Close**

Thank participants for their time and inform them of what happens to the information

## Appendix F: Qualitative data analysis

### Codes and Categories

A priori subcategories	Codes
Constraints/restrictions	understanding, diagnosis, communication, barriers, sensitivities, mental illness, employment, social relationships, stress, depression, anxiety, sensitivities, emotional distress, worry, limits
Mental health	stress, depression, anxiety, sensitivities, lonely, emotional distress, worry, isolation
Routines/patterns	preferences, limits, motivations, order
Parent health status	Coping, supportive, stress, mental illness
Informal support	daily living skills, tasks, money, bill paying, cooking, laundry, shopping, dedicated, social interactions, no friends, role
Formal support	GP, autism groups, psychiatrist, care worker, limited support
Parent strategies	determination, motivation, alternate ways, acceptance, facilitate, coping, consistency, inclusive, structure, dedicated
School experience	bullied, no friends, trust, limited socialising, alienated
Work experience	guidance, support, opportunities, volunteering, let go, productive
Changing role	mentor, responsibility/duty, transition, personal decisions
Future plans	nothing concrete, prepared, planned, process, safety, lonely, fear, vulnerability, mental illness
Support needs	financial, social, communication, acceptance, employment, independence, understanding, prompting, self-care, shopping, cooking, bill paying, monitoring, welfare support, health, diet,
Siblings	contentious/confrontational, supportive, little interactions, engagement, guilt, familiarity, protective, embarrassment, strained relationships
Abilities	self-care, transport, cooking, help around house, chores, independence, shopping,
Social interactions	limited social contact, bullied, friends, easily influenced, boundaries, understanding
Family dynamics	contentious, supportive, little interactions, teaching, antagonistic, father relationship, mentor, responsibility/duty

## Categories and Themes

Theme	Categories
A diagnosis of autism	Challenges/consequences Health Social relationships Family dynamics Experiences
The persistence and impacts of mental illness	Limitations/barriers Challenges/consequences Health Social relationships Priorities
Limited social networks	Support need Social relationships Family dynamic Roles and plans Experiences
Money management and exploitation risks	Support need Limitations/barriers Priorities Experiences
Contested family perspectives	Support need Abilities Challenges/consequences
Independent Living	Support need Limitations/barriers Challenges/consequences Priorities Experiences
Future support plans for adults with ASD	Support need Family dynamic Roles and plans

## Final themes and sub-themes

A diagnosis of autism	<p>The unknown: implications of no diagnosis in childhood</p> <p>The known: living with a diagnosis, knowing what to expect and do</p>
The persistence and impacts of mental illness	<p>Looking back: anxiety and stress a constant</p> <p>The overwhelming functional limitations of mental illness</p> <p>Looking ahead: vulnerabilities and concerns</p>
Limited social networks	<p>Bonding social networks of adults with ASD: 'getting by'</p> <p>Bridging social networks of adults with ASD: 'getting ahead'</p> <p>Linking social networks of adults with ASD: accessing formal support</p>
Money management and exploitation risks	
Contested family perspectives	<p>Contested perspectives of need between quantitative and qualitative reports of adults with ASD</p> <p>Contested perspectives with family members</p>
Independent living	<p>Transition to independent living and formal support services</p> <p>Practice lags behind policy</p>
Future support plans for adults with ASD	<p>Future support plans from parent's perspective</p> <p>Future support plans from the adult with ASD's perspective</p> <p>Future support plans from the sibling's perspective</p>

## Excerpt of coded transcript

<p>Contentious relationship in childhood</p>	<p>10 V: To start with C will you describe for me your relationship with C?  11 C: Well at the moment it's a brother role. He is in some areas a  12 mentor; he taught me how to shave. Badly mind you his instructions  13 weren't great. At the same time I also do feel responsible for him  14 and then sometimes it is my duty to cover and look after him when  15 his other carers are unable to do so. But I think it is healthy, a good  16 relationship. I think we both understand the roles we play and there  17 is no issues there.</p>	<p>sib relationship  role  mentor / engagement  responsibility (feel responsible)  duty.  care post parental  understand roles.</p>
<p>good relationship in adulthood</p>	<p>18 V: Have you always had a good relationship?  19 C: When he was younger we were less brotherly, more friends who  20 lived in the same house. We occasionally talked but that was it. And  21 then just before high school or after high school he slowly filled the  22 brother role by looking after me in school etcetera when I was too  23 young to do much else. Then with that transition I became more  24 incline to be a whatever I could be it didn't matter what that was,  25 homework or do social things with him to go to places with him or  26 to get a hobby so that he could join in as well. But that was high  27 school period when that kicked in. He often uses me as a punch bag.  28 He's got better with that he used to be quite not violent, not that  29 we kicked each other's heads in, but we did have some scuffs in the  30 past. Now it is more pokes and prods. He doesn't mind getting  31 hands on, but it is more verbal these days as well. That's fine. I  32 understand I don't take it to heart. It doesn't affect me because I  33 know we have our own little way of coming back I am a bit sarcastic  34 sometimes and he hates that. Last weekend we went to comic con</p>	<p>good relationship  contentious relationship  little interaction.  filled role of big brother  transition  more engaged, interactive  shared hobby.  good interactions  combative  antagonistic  confrontational  physical aggression.  verbal bantering  accepting  reciprocating  retaliation.</p>



responsibilities  
duties

Limited  
social contact

- 35 and we go to the comic shops together and we try to have a hobby  
36 and find our different roles. So the best extreme or the difference  
37 we have is I'm heroes, he's villains. So I can read all my hero books  
38 and he reads all the villain books and we can talk about it and  
39 discuss who would win the fight and just have a social debate but it  
40 is expensive.
- 41 C: I have friends that know my responsibilities about C and they  
42 often do things with me and C. I wouldn't say they were friends per  
43 say more a favour for me but that's because of his punch bag style  
44 ethic they don't fully get it which I can understand. And C does kind  
45 of get it we have had discussions with him about it before. I don't  
46 think there is anyone friend that we share.
- 47 V: Do you think that you spend enough time with C?
- 48 C: I think that I should spend more. Just because he doesn't talk to  
49 people, he used to do social things like online gaming and such but it  
50 has kind of declined recently. And I do feel like sometime I should  
51 talk to him a little more than I do. And often on the days that I do  
52 feel like that he is not around and on the days when I am not doing  
53 it I am in a bad mood or have other excuses. I do think I should  
54 spend more time.
- 55 V: What are some of the ways that you support C.
- 56 C: I work so financially sometimes. I try to teach him things and  
57 motivate him to do things. So he might not get a job but I try to

hobby / engagement

preferences

opposites

discussion  
social debate

responsibilities

favours / acceptance

don't understand

discussions - about  
engagement

time together

should be more

limited social contact

online activities

decreased engagement

guilt

bad mood / excuses

guilt / more time

not meeting personal  
expectations

How do you support it

financially / motivate

mentoring / teaching